

## **HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER February 2018**

### **Important February Activities on Hawai'i Island**

**February 12 from 1:30-2:30 Tai Chi/Chi Kung** with Maddy (Madeline Sofranac DPT). Come join people from the community at Tutu's House. Take a seat and come away feeling positive and optimistic the rest of the day.

**Exciting News—Weekly PD Exercise is Back!!**  
**February 5 & 26 (new day--Mondays) from 1:30-2:30 PD Exercise** with Maddy at the Allstar Crossfit Gym next to Tutu's House—same routine every class in the month with a mix of BIG & PWR moves, Tai Chi/Boxing and a version of Dance for PD. Minimal cost--\$5 or more per class or pay \$20-\$40 per month. *We need more attendees to keep these classes going, so please join us on Mondays!*

**February 14 from 1-3:00 Waimea PD Support Group talk story at Tutu's House.** Welcoming back past and new participants for open conversation on a wide variety of topics YOU want to talk about! Time has been extended, so we can talk longer if we want.

**February 16 from 2-5 pm Hilo PD Support Group** at Hawaii County ADRC for the Hilo PD Support Group's monthly discussion. *Please note change of date this month.* Speaker: Laurie K Mischley, ND PhD MPH, physician researcher from Seattle Integrative Medicine and Bastyr University--"The Next Generation of PD: What Does the Future Look Like?" Laurie speaks on many topics and you will have the opportunity to ask questions. Check out her website. Interesting retreats available: <https://educationismedicine.com/speaking>

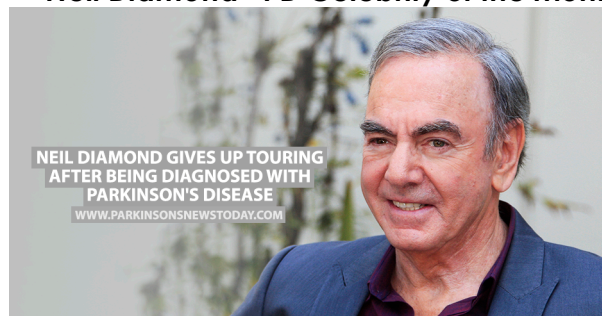
**Hilo PD Exercise**—every Wednesday from 9:30-10:30 am at the Hilo YMCA. Contact the Y at 935-3721 for more information.

### **Exercise is Medicine**

Typical weather forecast this time of the year-- Heavy rains and possible flooding on the Hamakua coast and Hilo. Windy conditions up to 35mph with higher gusts persist in Waimea and North Kohala, and lung stifling vog hanging over Kona. None of this is conducive to getting out for your much needed walk.

Many of our Island's support group members find other ways to keep moving in the spirit of maintaining a healthy lifestyle. This includes participating in available chair tai chi or yoga classes, riding their stationary bicycles, stretching exercises, and dancing to whatever music that is enjoyed, even if it's just limited to tapping your feet. If you can attend one of the group classes that's even better—you'll be able to utilize the energy of the instructor and other attendees. The key is moving the body and keeping the mind exercised as much as possible on a regular basis. It's so important!

### **Neil Diamond--PD Celebrity of the Month**



According to [CBS News](#), a spokesperson for the star said, "the onset of the disease has made it difficult to travel and perform on a large scale basis." Obviously Diamond was quite disappointed with his doctor's advice, saying he made the decision with "great reluctance and disappointment" and that he'd "remain active in writing, recording and other projects for a long time to come."

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### **Davis Phinney Foundation Worksheets**

Sue Lifschiz of the Waimea PD Support Group shares that nearly 40 helpful worksheets can be downloaded from <https://www.davisphinneyfoundation.org/resources/worksheets-and-downloads/>

Pat is an impassioned supporter of care givers/partners and over the years has started many support groups for this population. She is eager to help with care partner groups on our Island, and she plans to talk with the Waimea Support Group in the near future.

**Pat Bemis**

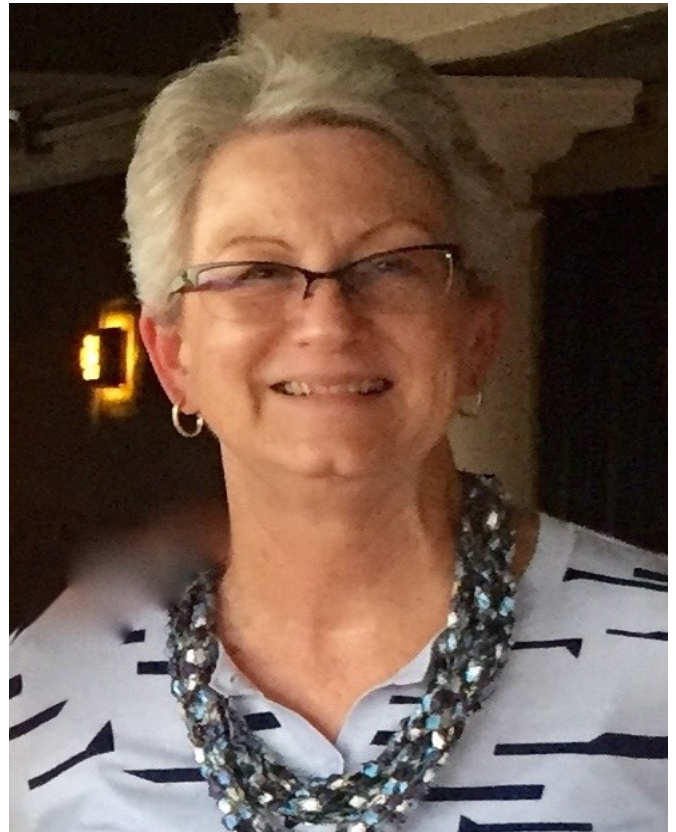
### **February 27 Parkinson Foundation Webinar**

This webinar, starting at 7am HST, focuses on the **treatment of psychosis, hallucinations, delusions, and paranoia found in patients with Parkinson's**. It will be conducted by Dr. Christopher G. Goetz, professor of neurological sciences at Rush University Medical Center, one of PF's Centers of Excellence. This webinar can also be viewed later by going to Parkinson Foundation online webinar site.

### **January 26<sup>th</sup> Hilo PD Support Group Meeting**

Pat Bemis, HPA Board member and care partner with her husband who has had PD for 30 years, attended and facilitated much of the January meeting, which was attended by 25 PWPs and their care givers/partners.

The discussion ranged widely, from the need for true managed care in Hawai'i to having a plan for care partner's possible illness, to the key point—balancing care giving with partnering/intimacy. Pat emphasized that the two main partner issues are communication and intimacy. She was VERY candid about the high level of sex addiction that can be caused by the drug Mirapex. She also stressed the importance of understanding that there is a high percentage of PWPs who have some type of addictive problem—gambling and shopping are the most prevalent. It was very helpful to be part of a truly open discussion about highly sensitive issues that affect PWPs and their care partners.



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### **From a PD Patient's Perspective By Joel Cohen**

Okay everyone--Valentine's Day is coming up, and it's time for me to be open and vulnerable by talking about my relationships with others in a loving fashion. Although tough to say, it would be a much worse trail to walk without their support and caring.

My wife, Phyllis, is of course, first on my personal love list. Whatever conflicts of communication and misunderstandings occur, she faithfully remains true to our mutual desire for love and sharing. I recognize that the continuing battle to deal with my daily, and sometimes long term challenges, with PD can cause her frustration, impatience and occasional short term anger that with communication, are mutually forgiven.

I refuse to be a victim of PD. Saying this, I can be over-reactive in my responses to her words of discord, regretting, after the fact, the way I respond. The fact is, Parkinson's is a challenge to our relationship.

In addition, it's way too common for me to forget to meet my responsibilities to contribute to our household chores in a timely manner. Getting me away from the computer to rest my mind and body and to sit down to dinner, which she has prepared, is often a challenge. Temporarily losing my balance or misjudging how far away I am from things and thus bumping into them, makes me bleed way too quickly. This requires her immediate, if not sooner, bandaging of arms and legs. Yes, being married to someone whose brain and body are not always in accord is challenging and HARD on both of us.

The good news is that we have found that taking time just to sit down to talk and express our feelings openly and in a listening mode work. Change is ever-occurring. So, continuing this communication is a must.

Having friends that care about us individually and as a couple is important. This includes the fellow members of our island's support groups. We do not feel alone in our pursuit of living life to its fullest thanks to them. Hopefully, our friends and support group attendees understand that Phyllis and I feel the same way about them.

Before ending this month's personal piece, I want to state three comments that I feel are so important to love and caring. (1) Understanding PD is so important. As you know, it's very complex with no two people having exactly the same symptoms. There are no simple solutions, at this point, to fix PD as a whole. (2) Acknowledging and recognizing my challenges without feeling the need to take care of me and identifying me as a victim of circumstance, is what works best for me. (3) A feeling of mutual compassion and gratitude contributes to a relationship that is good for both of us.

Wishing all a loving and thoughtful Valentine's Day that continues throughout the year.

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### **MJF January 16 Webinar on Genetic Discoveries**

Dave Iverson moderates MJF's 3<sup>rd</sup> Thursday webinars. You can access these easily understood and beneficial hour long programs at [michaeljfox.org](http://michaeljfox.org).

January's guest panelists include a patient, Anna Cohn Donnelly DHP, Roy Alcalay MD, and researcher Andrew Singleton PhD. Among items discussed are continuing research and findings of the SNCA gene linked to alpha-synuclein protein production and its effect on Parkinson's. GBA and LRRK2 genes were also discussed regarding how newly found data could be used to find treatments for specific symptoms. Studies and trials at various stages are occurring and researchers are encouraging participation. Go to the MJF website to learn more about them.

The next webinar is scheduled on **February 15** at 6am HST for early risers who wish to participate in the dialogue, and later in the day for most of us. February's topic is **"Depression and Anxiety in Parkinson's Disease."** You can find a variety of topics listed from past webinars on the site.

### **Parkinson's: A Looming Pandemic**

According to University of Rochester Medical Center neurologist, Ray Dorsey M.D. and Bastiaan Bloem MD, PhD with Radboud University in the Netherlands, new research shows that the number of people with Parkinson's will soon grow to pandemic proportions. They feel that it is important for the medical community as whole to be prepared for the challenge.

The doctors state that between 1990 and 2015, the number of people diagnosed globally with Parkinson's doubled to an estimated 6.9 million. By 2040, these numbers will grow to 14.2 million and will outpace Alzheimer's. These estimates are likely conservative due to underreporting, misdiagnosis, and increasing life expectancy.

As the number grows, the challenges that the Parkinson's community face today will increase, including an accelerated need to fund research in treating and preventing the disease, having adequate numbers of medical professionals with specialized expertise, and spreading knowledge that identifies Parkinson's early. An estimated 40 per cent of people in both the US and Europe do not currently see a neurologist and the number is much greater in developing countries.

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## **AND SO THE JOURNEY BEGINS.....**

**By Marlene Goodwin**

For a shopping list of reasons, Deep Brain Stimulation is not for everyone. Up until now, it wasn't for me either.

When my husband and I first read materials and watched videos of the procedure referred to as "DBS", we said to each other, "How frightening! Who the heck would have that done? OMG!"

During the initial office visit with my new neurologist, Dr. Allison Przekop, MD of Hawaii Pacific Neuroscience in Honolulu, the subject of DBS was brought up and discussed in depth. She was an obvious supporter of the procedure, and felt I was a good candidate for further evaluation and testing to see if that was a road I could, and should, travel.

Dr. Przekop recommended the Movement Disorder group at the University of California San Francisco Medical Center as the place to go. The doctors there, Dr. Ostrem and Dr. Larson, are very well known and respected in DBS surgery. That is all they do, and they have done 1000's of procedures over the past 20 years. As far as we were concerned, their credentials were impeccable. We waited four months for the first appointment. When the time came, we packed our winter clothes and took off for not-so-sunny "SanFranCaliFrisco."

Everyone at UCSF was prepared for our first half day of interviews, testing and information exchange. And everyone was so pleasant and professional too! All went better than expected.

Another appointment is scheduled in three months for a two-day session of further testing and evaluations, including psychological exams. If that all goes to plan, the actual surgery will then be scheduled.

We will try to chronologize our adventure going forward and share with you the Journey. Stay tuned! And as my husband always tells me, "It's not brain surgery, Honey!" Well, in this case it is.....

**Marlene and Dave Goodwin**



## **Managing Your PD Meds**

Much discussion has occurred regarding the use of Parkinson's medications, in particular, dopamine replacement drugs. "Managing Parkinson's Mid-Stride," a National Parkinson Foundation booklet, is an excellent reference to determine the amount and management of meds to ensure that dopamine production is continually present and working for you.

The booklet describes the "therapeutic window" as the period of time when there is enough medication to control your symptoms, but not too much to create side effects such as motor fluctuations or dyskinesias.

Data collected from NPF's Outcome Project is translated into diagrams that show typical models of on/off time and periods when the medication is most effective.

You can easily get an on-line copy of the booklet by going to [www.parkinson.org/pd-library](http://www.parkinson.org/pd-library).



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### **Political Involvement**

You have an opportunity to be a political advocate for people in the Parkinson's community. One way is to bring issues of need or concern to your State legislators. Individual members mailing addresses and office phone numbers of the State House of Representatives and Senate are listed on the legislature website at [www.capitol.hawaii.gov/](http://www.capitol.hawaii.gov/). Staff are available to answer questions regarding submitted legislation. You can track the progress of bills on the site.

You may also want to contact your representative's office to help educate members and to make them aware of the growing population and special needs of people with PD and their caregivers. Some political issues were brought up and discussed at the January 26 Hilo Support Group meeting.

Some of the current issues that relate to Parkinson's are:

1. Medical cannabis does not currently individually list Parkinson's Disease as a qualifying condition. You and your physician can go to the Hawaii Dept. of Health website [www.health.hawaii.gov/medicalcannabis](http://www.health.hawaii.gov/medicalcannabis) to submit proposals that request PD be added as a qualifying condition to use medical cannabis.
2. In order to see a medical specialist, including a neurologist who's a movement disorder specialist, those of us living on the neighbor islands often have to travel to Oahu. Insurance may not cover, even partially, the cost of travel and lodging making this an expensive trip for people with Parkinson's.

Hawaii's Island representatives, particularly Senator Josh Green and Representative Richard Creagan, both MD's, have taken leadership roles in support of people with health challenges. Check with their offices. You may want to support their efforts.

### **Caregivers/Carepartner's Corner By Phyllis Tarail**

Questions of the month—Is PD the main topic of your conversations with your PWP? What else do you talk about? Is it dominating your relationship? How can you be intimate if all you talk about is PD?

Here are some of my thoughts: Set aside some regular time weekly, if not daily, to talk to your partner about how things are going in your relationship. Be specific with your questions or concerns. Make sure to give yourself however much time you need and take turns talking and listening. In fact, real listening is more important than talking. Make sure hearing aids are in and working.

If you're interested in improving your relationship with your partner, let's talk more about these questions at the next Waimea Talk Story on Valentine's Day—that seems pretty appropriate.

### **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 February 23<sup>rd</sup> for the March edition.

We also encourage you forward this newsletter on to anyone who might be interested.