

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

**NOTE:** Information contained in this newsletter may be the opinions or editorial views of the writers & editors. We encourage our readers to conduct your own research.

### **Important August Activities News on Hawai'i Island**

**Maddy** (Madeline Sofranac) will **not** be teaching PD Exercise either in August or in September. Stay tuned to the September/October PD Newsletter for October dates and times when these classes will resume.

**August 8 from 1-3:00 pm Waimea PD Support Group talk story at Tutu's House.** The August meeting will focus on the immune system and PD. We strongly encourage readers of this newsletter to listen to the July 19 MJF webinar and come prepared to share your thoughts.

**August 31 from 2-5 pm Hilo PD Support Group** at Hawaii County ADRC. Please contact Fran Calvert at [fcalvert@hawaiiantel.net](mailto: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 is scheduled to begin in Hilo (not at the Y) in October. Contact Fran for more info.

### **Immune System Role In Parkinson's By Joel Cohen**

The July 19 Michael J Fox 3<sup>rd</sup> Thursday webinar discussion, facilitated by Dave Iverson, focused on the role of your immune system as it's related to Parkinson's. Guest panelists were Dr. Jeff Bronstein, Director of the Movement Disorder Program at UCLA and Todd Sherer PhD, CEO of the MJF Foundation.

I found that this webinar clearly answered a number of questions relating to my personal PD symptoms. There is so much that science and the medical community is learning, and so much more that needs to be explored. It is worth your time to listen to this webinar. It may provide both personal insight into the progression of your own symptoms and maybe open up possibilities of participating in current MJF studies.

One of the subjects discussed in the webinar includes research that attempts to find bio-markers to measure the impact of genetic factors such as LRRK2 gene.

A healthy immune system protects us against foreign entities and disease. On the other hand, autoimmune disease can happen when things go wrong. This particularly occurs with PWPs. Research continues. According to Dr. Bronstein, "It's about connecting the dots."

There is much discussion regarding the connection between inflammation and our immune system including imbalance in both brain and gut bacteria, a continuing discussion at support group meetings.

You can easily access this webinar by going to the MJF website and click on 3<sup>rd</sup> Thursday webinars.

The next MJF 3<sup>rd</sup> Thursday webinar is scheduled on August 16, which focuses on a common symptom of PD, urinary tract problems.

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### **PD Numbers Increasing**

The Parkinson's Foundation recently published an update relating to the estimated number of Parkinson's patients nationwide since 1978. This included combined data from multiple smaller studies in Hawaii, California, Minnesota, and Ontario Canada.

The data shows there were an estimated 680,000 diagnosed people in the US aged 45 and over in 2010. It is projected that this number will likely increase to 930,00 in 2020 and 1,238,00 in 2030, based on US Census Bureau projections.

Hawaii's Veteran's Affairs Pacific Islands Health Care System participated. Dr. Web Ross represented Hawaii in the study. Based on information received from Dr. Webb, the estimated prevalence of PD in Hawaii for patients age 45 and over is now 476 per 100,000 or 6800 out of our state population of 1.43 million. This is more than twice the number that the Hawaii Parkinson's Association has been using in community education outreach presentations.

It should be pointed out that as the number increases, more community education and medical professionals with expertise in treating PD will be needed.

### **PD Celebrity of the Month**



Alan Alda

On July 31, 2018, on the CBS This Morning television show, this well-known and well-loved actor revealed that he has Parkinson's disease, the first time he's publicly disclosed the diagnosis that he received three and a half years ago.

"I had been on television a lot in the last couple of weeks talking about the new podcast," Alda said on the show, "and I could see my thumb twitch in some shots and I thought, it's probably only a matter of time before somebody does a story about this from a sad point of view, but that's not where I am."

Though he was careful not to diminish the serious, even incapacitating symptoms that Parkinson's can bring, Alda said he wanted to warn people not to be "immobilized" by fear from the "very beginning." He said he stays active, taking boxing lessons and even marching to Souza music.

Alda said he's lived "a full life" since his diagnosis. "I've acted, I've given talks, I help at the Alda Center for Communicating Science at Stony Brook."

The 13-year-host of PBS' Scientific American Frontiers said he requested to be tested for the disease even before his doctor noticed symptoms. He'd read that one of the early symptoms of Parkinson's was acting out your dreams. "I was having a dream that someone was attacking me and I threw a sack of potatoes at them, but really I threw a pillow at my wife."

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## **NLY01**

A team of researchers led by professor Ted Dawson from the Johns Hopkins School of Medicine has developed an experimental drug similar to compounds used to treat an FDA approved drug for diabetes that slows the progression of Parkinson's and its symptoms in mice.

In experiments performed with cultures of human brain cells and live mice models, NLY01 blocked the degradation of brain cells that are evident in Parkinson's. The drug is expected to move to clinical trials this year. If successful in humans, it could be one of the first treatments to directly target progression of PD, not just the symptoms.

One of the team's experiments involved injecting mice with the alpha-synuclein protein and then treated with NLY01. Untreated mice injected with alpha-synuclein showed pronounced motor impairment, while mice treated with NLY01 maintained normal physical function and no loss of dopamine neurons.

Although Dawson does not anticipate any major roadblocks for use in humans, he cautions that more trials are needed to ensure the effectiveness and safety of the drug.

## **Parkinson's News Today**

Parkinson's News Today provides you with a great source of information regarding the latest in research efforts, activities occurring in the Parkinson's community, and personal commentary. It's easy to be added to their distribution list. Just go to the website, [www.parkinosnewstoday.com](http://www.parkinosnewstoday.com), and enter your e-mail address. They can also be contacted at [info@biowsservices.com](mailto:info@biowsservices.com). You will find it personally helpful and may create opportunities for you to bring up topics for discussion at support group meetings.

## **Rotigotine Patch**

The use of the Rotigotine patch was brought up at a recent support group meeting. It is a dopamine receptor agonist, which means it is located on the same receptors in the brain as dopamine and although not a cure for PD symptoms, it may be helpful.

The brand name is Neupro, also called rotigotine transdermal system, and it must be prescribed. It is not meant for everyone and it needs to be carefully monitored by your physician. Side affects are possible. The website states that people with liver issues should not take this drug. It is also important to review the use of other drugs and supplements for possible interactions.

## **Hawaii Parkinson's Association Walk**

This year's fund raising walk will be on Saturday, September 16 from 9am-noon. The setting is beautiful Magic Island, A La Moana Park in Honolulu for the second year in a row. Please check the HPA website, [www.parkinsonhawaii.org](http://www.parkinsonhawaii.org) for details and to sign up to walk or sponsor a walker.

Priorities for the monies raised include creating more opportunities for exercise classes and bringing at least a part time movement disorder specialist to our island.

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## **From a Person with PD's Perspective By Joel Cohen**

It's very important for me to express positive thoughts and alternatives to other people with Parkinson's and their care partners in this monthly column. Saying this, life is what it is. Major health challenges are now occurring for me and Phyllis.

This past month has been both physically and emotionally trying for us with likely more to come for at least the next few weeks.

We are dealing with a roller coaster of ups and downs that optimistically will end with a sense of mutual gratitude and, hopefully, each others' smiles that recognize the importance of our mutually supportive relationship.

It's Tuesday morning as I write this column for Phyllis' final editing and distribution. Tomorrow, she will be preparing for surgery in Honolulu on Thursday. It will be a 5:30 am pick up at the door by a friend for a flight to Honolulu and scheduled 11:30 am surgery. It's likely to take 3 hours under anesthesia for her and hopefully a time of minimal anxiety for me...stress being something that is all too frequent for me as person with Parkinson's under normal circumstances. This is a symptom that goes with the territory.

The surgery will be challenging for both of us in a number of ways. For Phyllis, it will be patience with herself in accepting temporary limitations. For me, it is a time to step up to the plate and provide needed support, both physically and emotionally, to her, especially during her recovery period.

The coming weeks will likely become a memorable time in our 30 year long relationship. We will be doing a bit of a role reversal as I assume caring for her and learn to recognize how Phyllis now takes on the day-to-day responsibility of supporting my efforts to be happy and healthy as possible. My hope is that our mutual challenges will be beneficial to our relationship, and the experience of it all will turn into something positive for both of us.

So, staying as upbeat as possible, let's see what happens. Expect Phyllis and I to talk about it at a support group meeting in the near future.

## **Newsletter Submissions**

This is **YOUR** newsletter!! We continue to seek your input on any subject related to PD—written by PWPs, care partners, members of the medical community, 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 August 24 for inclusion in the September/October edition.

Joel Cohen and Phyllis Tarail, Editors