

"When love meets pain, it becomes compassion. When love meets happiness, it becomes joy."

Jack Kornfield, Buddhist Teacher

Message from the Editors

The holiday season is upon us. There appears to be at least some sense of joy in the air. Our hope is that this feeling is present for you and those close to you and that it continues into the coming year.

Let this new year become a time of renewal that motivates us, as members of the Parkinson's community, to do what is necessary, within the scope of our capabilities, to be as healthy, happy and loving as possible for us personally, for family members, for friends that we cherish, and for others in our community who are in need of our support.

Wishing you the best of the holidays,

Phyllis and Joel

November 4, 2017 Hawai'i Parkinson Walk

The 2017 Hawaii Parkinson Walk, held on November 4 in Honolulu at Magic Island, was truly a success for HPA, the participants, and the many volunteers.

Over \$50,000 was raised from on-line contributions and monies delivered at the event. These funds will be used to raise awareness about Parkinson's and support Hawaii people living with PD and their caregiver/partners.

(Pictures by Rob Shallenberger—therefore, unfortunately, not in the pictures)



3 of Team Hawaii Island Movers & Shakers



The Start & End of the Race

Your Hawai'i Island Movers and Shakers team raised at least \$1357, which does not include checks that were sent to the HPA PO Box in the final days of the fund raising campaign. Mahalo to every donor, as amounts large or small all made a contribution to this annual event.

The day was also one to remember for team Hawai'i Island Movers and Shakers. Joel Cohen, Phyllis Tarail, and Rob Shallenberger began the day early at Kona International Airport, meeting up with Marlene Goodwin who flew in from Hilo. Our cab driver must have been new at his job, however, since with only "focus" of the above participants, the team made it to the venue on time for the 9am start. They were met by a host of volunteers, and with sign in hand received an enthusiastic announcement from the MC of their entry into the program area.

The accompanying pictures will best describe the activities that took place

Team members continued conversation over lunch at the airport getting to know each other better. It was truly a long, however, memorable fun day for all!



Getting Ready for the HPA Walkd

**From a Patient's Perspective
Joel Cohen**

January 31, 2005----so, it's been almost 13 years since my triple bypass open heart surgery, definitely a life altering event that motivated me to make some changes in my lifestyle and how I approach each day.

Prior to my surgery, a Catholic priest sat beside my hospital bed to comfort this then 62 year old guy of Jewish heritage during a time of uncertainty. He left me with a piece of paper reciting the Serenity Prayer. "Grant me the serenity to accept the things I can not change, the courage to change the things that I can, and the wisdom to know the difference."

So over time, I've made commitments to stay as emotionally healthy as possible. It's been an up and down battle for sure. Having Parkinson's disease clearly creates challenges making it a continuing work in progress to adhere to the following.

I will be present without excessive worry about the future or being stuck in the past.

I will have a sense of connection and recognize the support of others.

I will show compassion for myself instead of beating myself up for mistakes.

I will have faith in myself that even if things do not work out immediately, I'll be optimistic that they may in the future be possible.

I will know that no one has power over me unless I give it to them.

I will have a sense of humor, not taking myself too seriously, always trying to see the brighter, positive side of life.

I will appreciate what I have, accept what I cannot change, and be grateful for what life provides.

I will share my newfound sense of happiness and optimism with others.

That's my take on my Parkinson's challenge. I am placing these words of commitment on the wall next to my computer. It will be a reminder to me each day.

"When you can't control what's happening, challenge yourself to control the way you respond to what's happening. THAT IS WHERE YOUR POWER IS."

Anonymous

Meet Intrepid Physical Therapist, Madeline Sofranac

By Phyllis Tarail

Maddy, as those of us "regulars" at the Waimea PD Support Group call her, came to Hawai'i Island in 2013 via "divine intervention." After receiving her DPT (doctorate in physical therapy) at Northern Arizona University (with a specialization in neurological rehabilitation focusing on working with PWP's) in Flagstaff and completing her internships on the Navajo Reservation in Tuba City and in Alaska with a Native Alaskan Health Center, a friend from Alaska strongly suggested she come to Hawai'i Island and stay with his parents. This, after a log splitting accident caused her to chop off part of her finger when she realized that she could (and did) heal herself. As luck would have it, there was a job available in Waimea at Hawaiian Rehab Services, and she flew here to check out the job and decided to stay. Her friend's parents hosted her in Kohala for the first 3 months she was here. Alaska was just too cold for her and she really appreciated the cultural focus here, which reminded her of Tuba City. Surely coming here has been part of her spiritual journey.

In February 2014 Maddy gave a talk at Tutu's House on neuroplasticity and Parkinson's Disease, which led her to offer a movement class focused on PD and other neurological diseases. This, in turn, gave rise to the monthly Waimea PD Support Group at Tutu's House, now led by Joel Cohen and his wife, Phyllis Tarail and additional specialized PD exercise classes that Maddy has been offering weekly at the Allstar Crossfit gym next door.

Maddy now has office space at the Aloha Health Clinic where she can treat individuals every Wednesday. She can also treat PWP's at Mana Physical Therapy and at all patients at Body Pro, all in Waimea town. In addition, she's now teaching 10 classes a week in various water therapies and Tai Chi/Gung. Starting

in January she will be back to offering specialized PD exercise classes 3-4 Mondays a month from 1:30-2:30 pm at the Allstar Crossfit Gym. The first Monday each month she will be teaching the Chair Tai Chi/Gung class at Tutu's House, which is an excellent form of movement for PWP's and is highly recommended.

Her vision and her dream is to be part of an expanded Aloha Health Clinic that would include a warm pool as Maddy feels so strongly about the benefits of warm water therapy. The Clinic now (and then) includes chiropractic, acupuncture, cranio-sacral therapy and naturopathy as well as physical therapy. Maddy's passion is the neuroplastic model where things can always change and that many resources and options are available. You can check out her new website waimotionmadeline.com for more information about Maddy, her classes and her PD and other resources.



Maddy by the Warm Pool

Can Diet Treat Parkinson's?

by Joel Cohen

Yes, as is often said, "if you have seen one person with Parkinson's then you have seen one person with Parkinson's." Therefore, each PWP needs to determine what works best for them. Saying this, however, it's important to discuss with your personal physician or dietician prior to any radical changes in diet.

Dr. Rachel Dolhun talks about special diets in the Fall/Winter edition of Fox Focus on Parkinson's. She states, "When considering what to eat when living with PD, there are a menu of options, but no combination of foods have been proven to slow progression." As a general rule, doctors recommend a "balanced" diet that includes a variety of fruits and vegetables to maximize health and ease commonly found non-motor symptoms such as constipation and low blood pressure.

This article discusses the pros and cons of special diets. Emphasis is placed on being precautionary prior to embarking on one. Here are some examples that may be worth researching.

The Ketogenic diet is high in what is described as healthy fat and protein. It shifts the body's usual energy source from glucose (sugar) to fats (ketone bodies). The diet is strict and can be challenging to follow. Pre-clinical work and one open label study of PD patients support the potential for motor symptom improvement. A physician and dietitian must monitor blood work and watch for side effects such as dehydration or kidney stones.

Gluten Free diets exclude wheat, barley, and rye. Some individuals anecdotally report benefits. Pre-clinical or clinical evidence does not exist to promote using this diet for PD, and it could increase the risk of certain vitamin deficiencies. Care is also needed to ensure enough fiber intake for general health.

The Mediterranean diet focuses on fruits, vegetables, legumes, whole grains and "healthy fats" such as nuts and olive oil. Fish is a staple with red meat limited to a few times a month at most. Red wine is allowed in moderation with meals. The diet has been associated with decreased risk of Alzheimer's, heart disease and certain forms of cancer. Two studies also correlate it with a lower risk of PD, but further research is necessary.

The bottom line summarizing Dr. Dolhun's article... There is no single "Parkinson's diet." Creating a recipe for wellness must account for many factors including other medical conditions and your daily activity level. Treat diet like medication. Make significant changes only after discussing with your doctor and dietician.

Mohammed Ali--Celebrity of the Month with PD

January 17, 1942 – June 3, 2016



Thirty-six years after clinching an Olympic gold medal, a trembling hand lit the 1996 Summer Olympic Flame during the opening ceremony in Atlanta, Ga.

The hand belonged to the greatest boxer in the world, Muhammad Ali.

The significance of the moment far exceeded his title as 'The Greatest' heavyweight champion in the world who had defeated a list of boxing legends including Joe Frazier and George Foreman. Ali had spent the last sixteen years fighting a much more dangerous adversary and lighting the flame that July evening signified yet another victory in his battle against Parkinson's Disease. In those few seconds, Ali showed the world, "I have Parkinson's disease but Parkinson's disease doesn't have me." The image alone would inspire millions and epitomize the legacy of Muhammad Ali as "The People's Champion."

In 1997, Ali helped establish Muhammad Ali Parkinson Center at the Barrow Neurological Institute in Phoenix, a clinic, outreach, and research center dedicated to Parkinson's Disease. For the next ten years more than 23,000 research articles concerning Parkinson's Disease were published in scientific journals. In addition to increased awareness and research funding, Ali contributed to the current treatment regimen of Parkinson's.

As a result of his influence, it is now widely accepted that regular exercise, particularly when begun early after diagnosis, can reduce symptoms and greatly increase a patient's quality of life. Many centers, including the Muhammad Ali Parkinson Center, now integrate physical and mental exercise into the treatment of patients.

Emergency Preparedness

All PWP's, and probably their care partners, too, should consider the importance of wearing some sort of medical emergency ID, such as a bracelet or necklace that would provide emergency personnel with the vital information they need. Smart phones also have a place to include medical emergency info. Such items include a list of all medications with the dosing amounts and schedules, any allergies to foods or medication, and the name/s and phone numbers of who should be contacted.

It's equally important to be assertive with hospital personnel during and after procedures to ensure that they know that you have PD and what symptoms you are likely to be experiencing, such as tremoring, sweating, as well as communication issues (low voice volume, swallowing issues, etc.).

Important December Activities on Hawai'i Island

December 4 from 1:30-2:30 Tai Chi/Chi Kung with 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.

December 7 from 10:30 -11

Dress comfortably and be ready to move with licensed Zumba teacher Renee Morinaka at Tutu's House for an introduction to seated Zumba with upbeat music that stimulates both mind and body.

December 13 from 1-2:30 Waimea PD Support Group talk story at Tutu's House. Welcoming back past and new participants for open conversation regarding how you are feeling for the coming year. Right after the talk story, as requested, Madeline will resume her adaptive exercise class. Take a short break and move next door to Cross Fit Gym for an hour of movement and fun. Bring water and dress comfortably.

Note: Weekly scheduled exercise classes will be on **Mondays** beginning in January. More information to come.

December 5 through 26 from 1:15-2:30 at Kona Dance and Performing Arts In Kealahou join certified teacher, Marie Snyder EdD for Dance for PD. More information is available at 657-4473 or marie@isnydrs.com.

December 29 from 2-4 at Hawaii County ARDC for the Hilo PD Support Group's monthly discussion gathering with guest speakers from the Hawaii County Paramedicine Program who will talk about wellness, home safety assessments, and education preventing injuries.

YMCA exercise classes every Wednesday from 9:30-10:30 continue in Hilo. You can contact them at 935-3721 for more information.

Exercise is medicine. Life is what we make it!