

# PD SENTINEL

CONNECTICUT PARKINSON'S WORKING GROUP

FALL 2015

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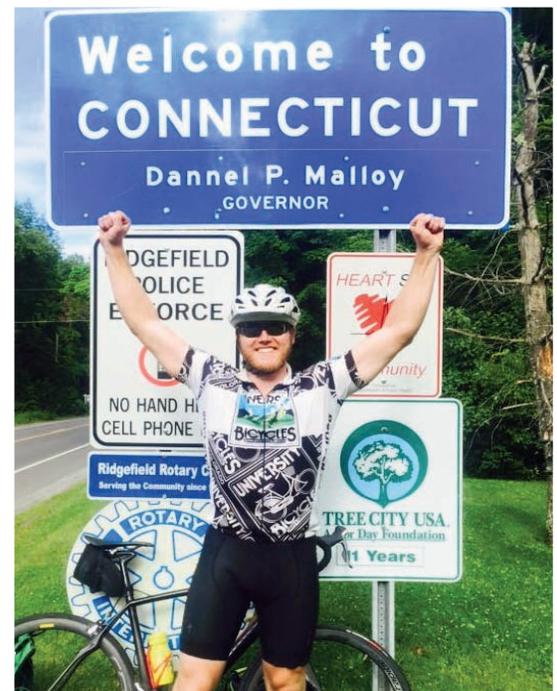
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## Going the Distance for PD

At 28, Henry Prescott is proving he has a kind heart and can go the distance. What distance? 3,400 miles by bicycle over 48 days. He covered varied terrains from Seattle Washington, to Portland, CT. Over hills and mountains, prairies and badlands, congested streets and cities, along side snow in the uplands, and through lightning storm. From camping to motels, from flat tires to bear cubs, to rough neighborhoods in Chicago he pushed onward.

Being a personal trainer and history student, Prescott will be working his way towards a degree in sports therapy. His interest in incorporating P.D. in among his chosen charitable donations is that he teaches a group of PWP.



Prescott cited anecdotes of getting lost, heading North instead of East and coming close to Canada's border. He was very impressed by the Continental Divide in Montana.

Raising \$31,000 he donated \$2,000 to our support group, and shared the details of his trip with us at a fundraiser at Portland Fireman's Ground on July 5, where we were well fed by Farrell's of Portland. Many thanks to Henry Prescott for including us as recipients.

# FROM THE EDITOR

## Editorial

By Kendra Hough



### FOREWARNED IS FOREARMED

In pondering the plight of a friend recently undergoing surgery, I felt myself becoming angry. She had undergone knee replacement and now was facing the postoperative complication of “confusion.” Having an ongoing diagnosis of progressive M.S., of a duration of decades, she was a setup. And the setup seems unexcusable despite the perhaps limited experience the floor nurse has on a daily basis with neurodegenerative disease and confusion found not so rarely in the elderly. Naturally I draw parallels between her M.S. and my P.D. We have found striking and spooky similarities in our courses through the past few years as well as some major differences. However I know that PWP are at high risk for postoperative “confusion” or POCD as they call it. Postoperative Cognitive Dysfunction.

I wondered if she had had a preoperative interview to assess her risks. This cognitive complication costs money, time, and sets the patient back in her striving for

complete and timely recovery to baseline.

Were her risks including those related to intra-operative medications like halothane, versed and benzodiazapines communicated to her caregivers? Were her risks related to postoperative sedatives and analgesics communicated to her care providers. Were caregivers trained in cognitive assessment that would ensure that earliest assessment and corrective attention would be forthcoming. Were psychosocial needs of the delirious elderly ascertained and addressed? Did her nurses know of the humiliation and blows to self esteem occurring with a blasé pronouncement of “confusion” in a proud, independent, cognizant woman? Was she referred to a geriatric specialist to intercede in this aspect of her care? What do you think?

“Confusion” is of great importance to PWP's as it sneaks alongside the shadowy threat of dementia.

### THE NEAT CENTER AT OAK HILL

This treasure trove of used/cleaned and repaired items for the disabled is housed in a defunct swimming pool and contains a vast offering of primarily durable goods. New England Assistive Technology, an Oak Hill Center, is at 33 Coventry St., Hartford, CT. The Equipment Center is open M-F 8:30 A.M. to 4:30 P.M., and 1st and 3rd Saturday 9-2. Phone 860-243-2869. There are centers in Stratford, Willimantic and Groton.

The items are priced less than half of retail. (I saw a sturdy walker for \$32). No age, income or disability levels are required. Donated items are assessed for

function and usability and are cleaned and repaired. Among items I saw were wheelchairs, canes, walkers, exercise equipment, transfer boards, commodes, weighted feeding utensils, safety-locks and bars. Many items were available to enhance the lives, independence and dignity of PWP.

Oops, I almost forgot! Need a part? Don Hoerman, assistive technology specialist bets he can find it!

So swing by NEAT and check it out. It is disability accessible.

# FROM THE PRESIDENT

## Progress Report

By Jeffrey LaGrange



I can hardly believe it but it's true. Halloween has come and gone, we've turned our clocks back an hour and now we are concentrating on the holidays once again. The year of 2015 was a wondrous and wonderful year for CPWG. It was a year of growth, moves, donations and surprises.

Our move was to The Village at South Farms where we are now very nicely settled. We've scheduled some great speakers and will do so for next year (we already have two) but we're going to spotlight our own members every other month if possible with an open mic where we can share our good times and our bad and hopefully hear some wonderful stories and get some help while making new friends.

Our growth was in our membership and outside donations as well as in our classes. Along with Laura's Dance class that began about eight years ago, we now have a terrific exercise, stretching and voice work class on Tuesday at the Middletown Senior Center. Tracey joins Laura as another one of our dedicated teachers. I urge you to check them both out or to ask at the meeting or Senior Center for more information and a flyer.

Our donations were very healthy this year and our donations were often a surprise this year. I remember one morning in the summer getting e-mail from a board member asking me to check into a young man named Henry Prescott. I did and it turned out that it was Henry who rode his bicycle from Oregon clear across the country ending up in his hometown of Portland, CT. He was raising money for Parkinson's and wanted to give some money to our group. So Henry's family and friends gave him a welcome home picnic with ALL proceeds going to CPWG. We ended up getting a donation right around \$2,000 which Henry wanted to put toward the exercise class – being an exercise teacher himself. Next a Women's

Golf League who was having their yearly fundraising event thought it would be good to give some money locally to the CPWG. Of course we were honored and the women raised just about as much as Henry, around \$2,000. Add to this our yearly donation from the golf community at The Farms Country Club in Wallingford in memory of Lenny Zwick and you get a sizeable donation to keep our Dance class going for a full year and to keep Tracey's class very healthy.

On the flip side CPWG was in a very positive growth and financial position for the bulk of the year. With all the above-mentioned donations, we also had our annual appeal letter go out in late February and it was well received. Our members went up to bat and kept us going, again. The Board met in the early summer to discuss how we could give since we were good at receiving. We voted overwhelmingly to donate \$3,000 to the Michael J. Fox Foundation. That money was matched by a donor who wishes to remain anonymous but has pledged to match every donation to the Fox Foundation up to fifty MILLION. So we can say we donated \$6,000 to the Fox Foundation plus CPWG voted to make a \$250 donation to the CURE Now PD research fund.

We are honored by everyone who donates to our group and to all the people that attend our classes at the Senior Center and put in a dollar or two each week to help out the teachers with supplies and travelling expenses. So you see it was a great year all around. Growth in our classes and surprises from people wanting to give to help find a cure for Parkinson's. All my reading says that they are very close with a tremendously full pipeline of potential drugs in the very near future. Like Michael J. Fox says wouldn't it be great if Parkinson's was cured or at least totally manageable and we could all just meet as friends and not friends with PD. Someday soon!

# Editorial

## MADPA SYMPOSIUM

The 2nd annual Madpa Symposium was held at University of Hartford on July 18th. It was well attended, hopeful and was filled with evidence based information presented by esteemed speakers committed to our cause. The topics covered new therapies in P.D., surgical intervention, depression and a unique adaptation of the idea of exercise and dance ... that was quirky and fun!!!

Some smaller topics discussed was the use of melatonin for sleep...in a time released formulation.

Also the use of medical marijuana, not just for pain but also for weight gain and for sleeplessness. Rescue meds for P.D. were also addressed, with informational literature on Rytary which increases on-time. Alpha-synuclein remains a forefront topic for investigative research.



Steve DeWitte presents a participation plaque to MDS Fiona Gupta

CPWG members Martha Jaffee, Vicki Smith and Geoff Smith greet and sign-in attendees



Keynote speaker Pamela Quinn gives an inspirational talk and gets attendees moving during the luncheon.



MADPA team with presenters: Jill Baldwin, Karl Hespeler, Michael Pourfar, MD, Michael Hahn, Fiona Gupta, MD, and Steve DeWitte

## AARP "ROAD TO LIVABILITY" PROGRAM

Tia Murphy, volunteer, presenting AARP's Road to Livability Program at our August 15th meeting, was proud to share the news of passage of the Ct Care Act. Fulfilling the goals of AARP, this new law facilitates and supports the option of aging in place.

With her colleague, Jean, also a volunteer, Tia brought examples of the NEAT equipment available to enhance the possibility of disabled and seniors to accomplish that goal. Also discussed were specific options available for aging in place with regards to such things as no-step entrances, outside lighting choices, entry width ranges



for wheelchairs and walkers, raised toilet seats, use of grab bars, railings, anlever door handles, as well as ramps, stairmasters and pullout drawer.

Mentioned also was the on-line AAR drivin course.

We were referred to CAPS Certified Aging in Place Specialists ... available to hire for your own needs assessment. Tia and Jean were enthusiastic about their roles in delivering this information to us.

Suggested CAPS specialists include:

In Guilford ..... [flamandbuilders@sbcglobal.net](mailto:flamandbuilders@sbcglobal.net)

In Durham ..... [sharon.mccormick@mindspring.com](mailto:sharon.mccormick@mindspring.com)

Also in Durham Henry and Priscilla Racki.....

..... [henry@rockfallco.com](mailto:henry@rockfallco.com)

## DECUBITI: DECREASE THE RISKS

Do you think you are safe in bed? NOT! (as the kids say). I could tell you of many hazards but will restrict myself to decubiti a/k/a bed sores aka pressure ulcers. Decubiti are not specific for PWP but occur in many illnesses that involve impaired mobility. The bedbound and chair-bound are at high risk. Christopher Reeves was just one of many whose outcome was allegedly affected by decubiti. Although sometimes assumed to signify neglect in care, that is not always the case.

The main requirement for pressure sores is: pressure. It is the weight of your own body — your skeleton, muscles, etc. — that applies pressure to your skin and underlying tissues sufficient to cut off the blood supply and thus oxygen to the pressed area. The red, white and blue sequence of color changes are seen as tissue is damaged leading to tissue death. The changes in color are actually inflammation, blanching and cyanosis. Among the body parts very apt to be involved are shoulders, elbows, heels, sacrum, and hips.

Both prevention and healing can be difficult, but the approaches are similar. Cleanliness, smooth linens, good

nutrition and hydration are essential. Motion is absolutely prime. Turning side to side, or being turned often in bed, getting out of bed to chair or standing by yourself or with assist is helpful for prevention and healing. Relieving the continued pressure allows oxygen rich blood to facilitate repair. There are many products marketed for care, but motion is prime.



PWP are champions of decreased motion. A good start to remedy this as it relates to the prevention of decubiti is the use of a bed-rail to assist turning.

## MUSHROOM SUGAR

In browsing the internet looking for natural substances that may alter the misfolding of alpha-synuclein, I came across a mushroom sugar called trehalose. The more I read the more excited I became. The material was in a blog by a Harvard grad named Vince Guiliano ... not a scientist but a computer expert with a strong interest in aging and neurodegenerative disease. Over many years he has collected a list of studies on these topics and was wondering why no human trials have been conducted on this substance

Trehalose is a natural simple sugar prevalent in lower organisms, like shrimp, bees and mushrooms. Shiitake has the highest percent of the varied mushrooms. Trehalose is already approved by the FDA as a sweetener for human consumption. It is available for sale in this country (ie. Amazon.com) and has been used as a sweetener in Japan for a long time.

It allegedly is not found in the bodies of mammals, however many of them contain trehalase the enzyme that converts some of it to glucose in humans. In animal experiments it does some exciting things that have implications for PWP. Among the findings are that it stabilizes proteins, produces a positive outcome on stress and aging. Of particular interest is the role it plays in “housekeeping” within the body. By this what is meant is its role in clearing aggregate prone proteins ... like mutants of alpha synuclein and tau and disease causing prions. There is suggestion that it crosses the blood brain barrier making it accessible not only to gut-present but also to brain-present interlopers.

My feeling was first “wow”, and secondly that this might be a “too good to be true” account. Imagine my surprise to find a clinical study being funded by Michael J Fox on his list of funded grants. It is in Toronto and is entitled “Development of Trehalose as a Disease-Modifying Treatment for Parkinson's Disease. Several studies have been developed to enable non-human primate trials to begin. They are looking at optimal brain and plasma levels and since it is already FDA approved will anticipate moving it to clinical trials. Laboratories listed are Junaxo, Inc. and Atuka, Inc.

# LIVING WITH PD NATURALLY



By Martha Jaffe

*Holistic Medicine is a form of healing that considers the whole person — body, mind, spirit, and emotions — in the quest for optimal health and wellness. According to the holistic medicine philosophy, one can achieve optimal health — the primary goal of holistic medicine practice — by gaining proper balance in life.*

*Holistic medicine practitioners believe that the whole person is made up of interdependent parts and if one part is not working properly, all the other parts will be affected. In this way, if people have imbalances (physical, emotional, or spiritual) in their lives, it can negatively affect their overall health.*

*A holistic doctor may use all forms of health care, from conventional medication to alternative therapies, to treat a patient.*

My name is Martha Jaffe and I'm your newest board member; I've chosen the title Holistic Advisor because I'd like to share some of the unconventional treatments I've been using to treat my PD. I've been diagnosed with PD for almost 4 years but like a lot of you my diagnosis took a long time and I've probably had it for 8 or more years based on symptoms. I've chosen to treat my PD with a combination of holistic medicine with some traditional (aka western) medicine thrown in.

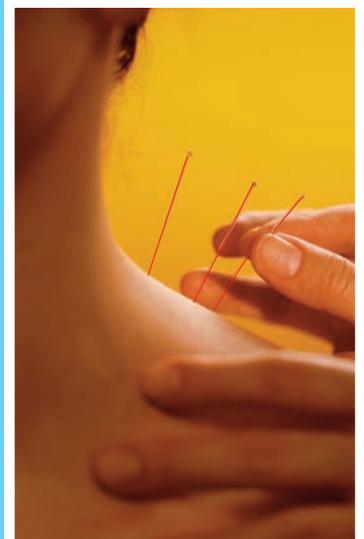
My first line of defense is getting exercise on a daily basis, taking vitamins and supplements and being very careful of what I eat; I've been gluten, dairy, soy and yeast free along with a low-sugar, nutrient dense diet for several years now. Fortunately, I love to bake and create my own recipes so that hasn't been a big issue for me. I used to have all manner of stomach issues including GERD, IBS and constipation but since I've started this diet most of these issues have been resolved.

One of the exercises I highly recommend is a form of Tai Chi called Qigong (pronounced chee-gong) which basically means "vital energy cultivation" or "mastery of your energy"; it's really more a way of life than strictly an exercise program. I've been taking a class at my local community center once a week for the last 2 years that incorporates an 18 form moving meditation followed by a seated meditation. I also perform the moving meditation at home 3 or 4 times a week. Since taking the class, my balance and anxiety levels have improved dramatically.

I'm also a big fan of acupuncture. I first started using acupuncture for my migraine headaches. Thankfully I no longer have these, but I've kept up the acupuncture for some of my PD issues such as pain, constipation and it even helps with my tremor.

Thanks to the influences of Qigong and acupuncture, I've started to employ other stranger therapies such as essential oils and healing crystals to treat some of my PD symptoms and other ailments. My philosophy is why not try anything, but even I was surprised to find that using a few healing crystals along with some essential oils has allowed me to get the best sleep I've had in probably 20 years. I also typically carry around some crystals with me during the day to help me feel grounded and energetic.

If anyone would be interested in hearing more about these let me know at one of the meetings or you can contact me via email at [martha.jaffe@cpwg.org](mailto:martha.jaffe@cpwg.org).



# CARE PARTNERS REPORT

## Clear and Simple

By Lisa Burt



*Summary created utilizing article from Cindy Laverty, caregiver coach, radio talk show host, and author of "Caregiving: Eldercare Made Clear and Simple."*

"The very essence of being a human being is feeling like we have a purpose. We were put here to live our lives in abundance. When you get into caregiving you tend to live in lack." Caregiving is like a four-legged stool comprised of physical, emotional, intellectual, and spiritual elements. To feel that their lives have meaning and purpose, a caregiver needs to have all four legs in balance.

The problem, according to Laverty, is that most caregivers spend their time teetering on only two: the physical and the intellectual. Another way to look at it is that most caregivers concern themselves with two main questions: 'What do I need to do to care for my loved one?' and 'How do I do it?'

### **Re-balance and re-purpose your life**

Having a purpose in life doesn't mean you have to aspire to become the next Gandhi, or Mother Teresa. It simply means making the time to do what you love to do.

**Acknowledge and separate your purposes:** Laverty says it's vital to admit that you have made a choice to care for your loved one. "There's no law that says you have to be a caregiver, to give up your life. When you know that you have a choice, then your attitude changes. You get to say no, to make decisions." When it comes to caregiving, your role is not to give up your life to fix everything that is wrong in your loved one's life: it's to help them live in as much dignity and grace as possible, given the situation.

**1. Make a plan:** A plan means asking some difficult questions about you and your loved one's future and making some tough choices regarding finances and advanced directives. This also means knowing when you need to take a break from caregiving, and learning how and when to ask for help. Try to make sure you have access to a personal support system of doctors, family, friends, counselors, support groups, etc.

**2. Set some boundaries:** Take the time to erect those boundaries now. According to Laverty, the limits we set with the other people in our lives play a huge role in determining how those people treat us. It might also help to compile a list of things that you can do, can't do, will do, and won't do when it comes to taking care of your loved one.

**3. Set some goals:** The important thing to remember with goal-setting is to take it in steps. Laverty suggests setting small, medium, and life goals, and working towards them in an incremental manner. Remember to reward yourself along the way when you achieve one of your targets.

**4. Scare yourself:** There are a whole host of reasons that a caregiver can throw out as to why they don't have the luxury of living a life with purpose. But, according to Laverty, these excuses are just the mind's way of remaining in its comfort zone. "We are conditioned to stay stuck in our spot," she says, "because going out of it is just too scary." If you feel like your life is being consumed by caring for your loved one, it might be scary to admit that you matter too. Go ahead — scare yourself.

**5. Discover your higher endeavor:** Laverty says care can begin to re-ignite their personal passions by asking the questions: "How do I find adventure in the day-to-day drudgery? How can I go to a place of higher endeavor?" It's easy for a caregiver to get caught up in the minutia of caring for their loved one that they forget how to answer what their higher calling is.

The key is learning to give yourself permission to live your own life—no excuses. Laverty says, "If you had the opportunity to go back, and sit with the person you're caring for and ask, 'Would you want your child to lose their life to care for you, the answer will almost always be, 'NO.'"



52 Princeton Drive  
Middletown, CT  
06457

# Calendar

**Disclaimer:** The content of this newsletter is offered to our readers solely on an informational basis and is not intended to support any medical treatment or advice. You are encouraged to review information regarding treatment with your physician. The opinions expressed are those of the writer or presenter and do not constitute an endorsement or approval by the CPWG Board or Newsletter staff.

## CPWG Activities:

**Regular 3rd-Saturday-of-the-Month Meetings, 10:00a.m.-Noon. The Village at South Farms 645 Saybrook Road, Middletown, CT Visit us at [www.cpwg.org](http://www.cpwg.org)**

**November 21 – Officer Anthony Knapp, from Middletown Police, Community Relations will join us.**

**December 19 – NO MEETING THIS MONTH  
*HAPPY HOLIDAYS!***

**January 16 – Marie Coughlin will be our guest. Topic will be “ Making sense of all senior housing options”.**

**February 20 – Open Mic Meeting**

## Events:

**Radio Parkies "DJ Pete", listen to Connecticut's own Peter Northrop every Tuesday from noon-1 p.m. for his world-wide internet radio program at <http://www.radioparkies.com>.**

**Save the Date for the 2016 World Parkinson Congress, September 20-23, 2016 in Portland, Oregon. Our Make a Difference Parkinson's Alliance (MADPA) will be sending a delegation from Connecticut. MADPA will also be providing scholarship assistance. If interested contact Jill Baldwin [jerseyisle@hotmail.com](mailto:jerseyisle@hotmail.com), additional information to come!**

**Connecticut Advocates for Parkinson's (CAP) announce that a new support group chapter has been formed in Branford, CT. For more information go to <http://parkinsonsct.org>.**