

PD SENTINEL

CONNECTICUT PARKINSON'S WORKING GROUP

SUMMER 2016

In this Issue

Thanking Jackie!
page 1-2

Care Partners
Report
page 3

My Parkinson's
Journey
page 4-5

FYI
page 5

Living with PD
Naturally
page 6

Humorous
Side of PD
page 7

Resources Guide
page 7

Calendar
page 8



Thanking Jackie!

As the current president of Connecticut's Parkinson's Working Group there are a handful of wonderful things I get to do. Aside from being given generous dona-

tions to keep our two classes going at full tilt at the Middletown Senior Center, I get the privilege of getting to recognize wonderful people who do great work.

Continued on page 2

Thanking Jackie!

Continued from page 1

One such person, really in a class all her own, is Jackie Dorwin. Jackie was one of the founders of CPWG many years ago, along with Stan Wertheimer who happened to pass away just a month or two ago.

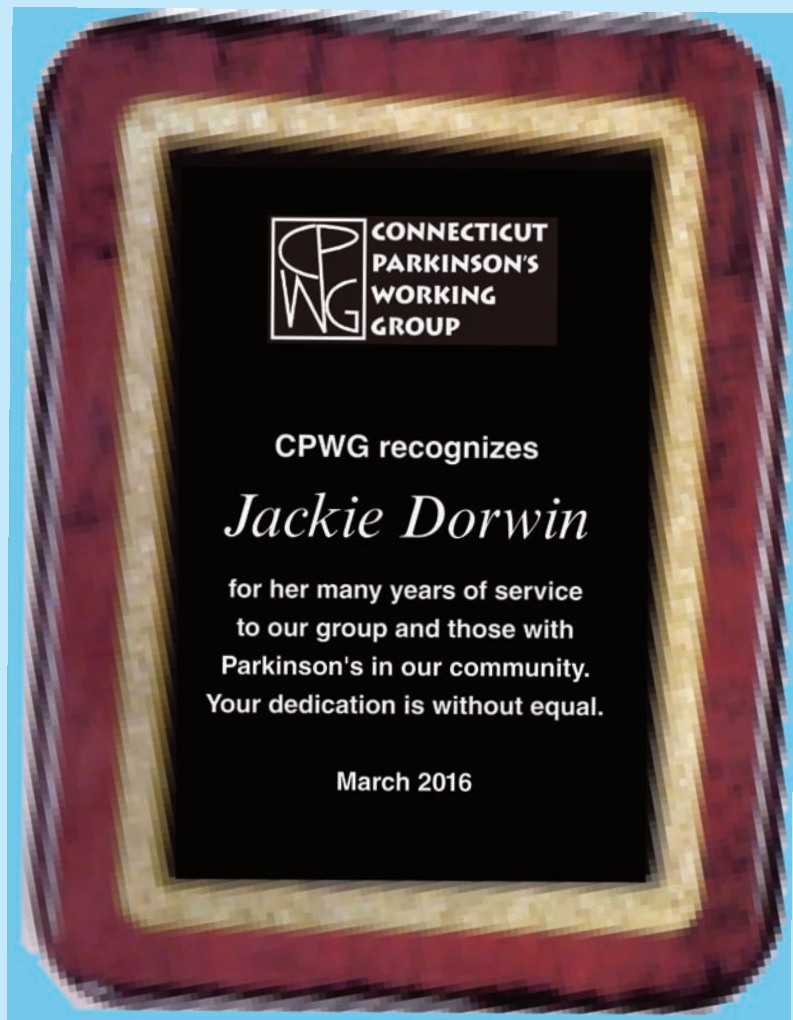
Luckily for our group, Jackie is still going strong and is a key player in the group. It is because of this current work, her non-stop involvement in all of what we do, plus being one of the founding members of the group that the Board decided to honor Jackie.

I had a plaque made up and had the great good fortune of reading it aloud to her at one of our recent meetings. Along with a dozen roses, we felt it was the least we could do to recognize such a tremendous force in not only getting the group started but also in keeping it running for many years with more and more involvement in the community

I must thank her husband Chip for being a wonderful help to us all in not only getting her to the meeting, but keeping this presentation top secret.

Now that the cat is out of the bag, please join me, once more, in honoring a wonderful, tireless worker and leader in making the group a success that it is today. Jackie Dorwin we all give your our applause ask you so much for all you have done and hopefully will do in the future.

By Jeffery LaGrange



CARE PARTNERS REPORT

The Aware in Care Kit

By Lisa Burt



Did you know that three out of four people with Parkinson's disease do not receive their medications on time when staying in the hospital? People with Parkinson's visit hospitals more often, and, combined with the great importance of the timing and dosing of Parkinson's medications, face greater risks in the hospital.

This is why the National Parkinson Foundation (NPF) has launched the Aware in Care program, which aims to help people with Parkinson's disease get the best care possible

during a hospital stay.

To protect, prepare and empower people with Parkinson's before, during and after a hospital visit, NPF has developed a free Aware in Care kit with tools and information to share with hospital staff during a planned or emergency hospital stay.

The kit is large enough to fit your Parkinson's medications to take with you on your next trip to the hospital.

THE KIT INCLUDES

Hospital Action Plan

Read about how to prepare for your next hospital visit—whether it is planned or an emergency.

Medical Alert Card

Fill in your card with emergency contact information and place in your wallet.

Parkinson's Disease Fact Sheet

Share the facts about Parkinson's with hospital staff and ask that a copy be placed in your chart.

Thank You Card

Present this card to a staff member who provides high quality care.

Magnet

Use this magnet to display a copy of your Medication Form in your hospital.

Parkinson's Disease ID Bracelet

Wear your bracelet at all times in case you are in an emergency situation and cannot communicate.

Medication Form

Complete this form and keeps copies in your kit for use at the hospital.

I have Parkinson's Reminder Slips

Share vital information about Parkinson's disease with every member of your care team in the hospital.

Get Yours Now!

www.awareincare.org or 1-800-4PD-INFO (473-4636)

***Article from the National Parkinson Foundation**



I'm a homebody at heart. The safety net provided by my family and home nourishes my sense of wellbeing. Being sheltered by such a warm and fuzzy feeling makes living with Parkinson's disease a bit easier. All the same, too much of a good thing is not healthy. Protecting yourself from every bump in the road and surrendering to each challenge in fact limits your ability to live well.

Parkinson's, like a parasite, has taken up residence in my body. Its army of symptoms is plotting a coup against me. These symptoms are rude, bossy and show no mercy while demanding that I abide by their commands. My initial defense to this attack was to add another protective layer of bubble wrap and retreat to the security of my comfort zone. It was easy to be passive while sheltered from the enemy. But, refuge can float you farther away from the familiar, as if lost in space. But as luck would have it, I heard the robotic voice of my inner warning system blast out loud and clear "Danger, Jill Robinson!" The message of this cautionary tale is that the smooth path at the fork in the road is not always the best choice.

During the summer of 2015, extreme athlete Sam Fox, whose mother has lived with Parkinson's disease for over 10 years, organized the Tour de Fox fundraiser for Parkinson's research. Sam, along with members of Parkinson's communities across the country, climbed the highest points of the 48 contiguous states. Tour de Fox raised well over one million dollars for the Michael J. Fox Foundation's (MJFF) Parkinson's research.



Thank you Sam. I had the privilege of being part of Team MADPA, a group of people from the Make a Difference Parkinson's Alliance in Connecticut, who climbed Mt. Frissell, the highest point in Connecticut at 2,380 feet elevation. (To me it might as well been Mt. Everest!) I am proud that our team's effort raised over \$13,000 for Tour de Fox.

My seven year old granddaughter questioned the wisdom of my decision to take part in the Tour de Fox climb when she worriedly asked her mother, "Should Grandma be climbing a mountain?" Hiking along trails in the woods and climbing mountains are out of character for me and not on my list of leisure time activities. My preferred stroll is exploring the neighborhoods of New York City on foot with my husband. Typically, we start our day in the East Village and meander up to the Farmer's Market at Union Square, then we make our way to Central Park for a leisurely afternoon. We end the perfect outing with dinner at our favorite little Italian restaurant on the upper west side.

I joined Team MADPA because I believe in our cause to raise money for Parkinson's research. But one question still needed to be answered. Not why would I climb a mountain? Not should I climb a mountain? But, could I climb a mountain? Bound and determined to climb with Team MADPA I began my preparation. First, I bought a sensible pair of shoes. Apparently one doesn't climb a mountain in cute little sandals. Second, I purchased hiking poles which proved to be one of the best investments I've ever made. The poles were essential for me to maintain balance as I climbed and I now frequently use the when I go for a walk. Next, a bit of training on our local hiking trail, where I practiced using the poles and not screaming when I saw a snake. My husband and I even took a scouting trip to Mt. Frissell. (Oh my, driving up to the beginning of the trail was scary enough for me!)

The beautifully warm and sunny June day arrived and off we went to Mt. Frissell with my new equipment and a backpack filled with water, snacks, bug spray and my last will and testament. Like clockwork everyone arrived. It was so exciting to meet Sam Fox and his crew from MJFF. They were truly amazing, professional, organized and fun to be with.

I was so excited to be climbing with my fellow team members both with and without Parkinson's. Especially my



friend Joni who also has Parkinson's. I'm a good 16 years older than Joni, too old to be her sister, too young to be her mother, but we complement each other and enjoy a wonderful friendship. We started the climb side by side, but Joni's youthful advantage and experience climbing outperformed my novice abilities. Actually, as one of the oldest climbers with Parkinson's in the group, I was passed by everyone except of course my dear husband who had my back all the way to the top. But Joni was there for me as I ascended, her constant shouts of "You can do it Jill, keep moving!" echoed back and gave me confidence. I was so motivated to push myself up that mountain that not even the appearance of a slithering snake could have broken my stride. And when I finally made it to the top, Joni was there waiting with open arms and a gigantic hug. The view was spectacular, the feeling of accomplishment glorious. I would climb Mt. Frissell again in a New York minute!



The trek up Mt. Frissell was definitely not the easy tranquil path at the fork in the road. It was incredibly difficult and I still can't believe that I scaled up rocks let alone made it to the top. Likewise, descending the mountain was equally difficult for my exhausted stiff body and shaking legs. Conquering the rugged road taught me I'm stronger than I imagined. There is no doubt that Parkinson's will present me with new challenges in the future. I'm ready. There is no need to live wrapped in plastic bubbles or be afraid of the future. With the right equipment, training and people cheering me on, I can overcome the obstacles ahead and live well with Parkinson's. The coup has failed.

My family and home will always provide me with that warm and fuzzy feeling of wellbeing and knowing that I have a safety net is comforting. I've become a homebody with a heart for an adventure, every now and then!

FYI FOR YOUR **INFORMATION**

PWP's Making a Difference at the WPC!

The 4th World Parkinson Congress is coming to Portland, Oregon, September 20-23, 2016!!

Are you interested in attending?

For information about the WPC 2016 visit

<http://www.worldpdcoalition.org/?page=PortlandCountdown>

WPC gathers every three years and MADPA representatives will be attending. MADPA will be raising funds to provide assistance for those attending.

If you are interested in being part of the CT delegation please contact Steve DeWitte

sdkeepthefait@gmail.com or

JillBaldwin@jerseyisle@hotmail.com.

3rd Annual MADPA Summer Symposium

The 3rd Annual MADPA Summer Symposium is July 16, 2016 at the University of Saint Joseph, West Hartford, CT. The symposium is a free day long event with prominent morning speakers, lunch, keynote speaker and afternoon breakout sessions. For more information or to register contact Jill Baldwin at jerseyisle@hotmail.com or 860-658-0293.

LIVING WITH PD NATURALLY



Overnight Blueberry Oatmeal Recipe

By Martha Jaffe

I came across something called overnight oatmeal a while back and was excited because it's easy to make, is easily customizable (calories and protein can either be increased or decreased easily to meet your needs) and it provides a ready-made breakfast in the morning. You can put it together during your on-time the day before and then you don't need to worry about making something when you first get up.

Overnight oatmeal is hard to screw up so play around with the recipe by adding different kinds of fruit and flavorings. If the oatmeal winds up too wet simply add a few more oats to compensate. If it's too dry add more liquid.

Basic Recipe: (normally makes 2 servings but if you need to gain weight you can eat the entire batch)

- ½ cup old fashioned rolled oats
- 1 ½ to 2 teaspoons almond or vanilla extract
- 1 Tablespoon chia seeds or ground flax seeds*
- 1 Tablespoon almond butter*
- 1 ½ - 2 teaspoons ground cinnamon
- 1 Tablespoon coconut oil*
- ¼ teaspoon dry stevia or 30 drops liquid

- 1 Tablespoon fruit sweetened blueberry jam*
- ½ cup + 1 Tablespoon filtered water
- ½ - ¾ cup frozen blueberries

Put the dry ingredients (oats, chia, cinnamon, stevia) in a medium sized container (I like to make this in an old nut butter jar) and stir or better still shake (since we're so good at this) together. Melt some coconut oil by placing the container in hot tap water for a few minutes. Meanwhile add the water, extracts and nut butter to the mixture and stir to combine. Add the coconut oil and stir to combine, make sure you don't add the frozen blueberries until the coconut oil is incorporated or it will harden up before you can mix it in. Finally stir in the blueberries and put in the fridge until the next morning. It will have a pudding like consistency in the morning. If you prefer it warm, heat it in the microwave for a 30 to 45 seconds.



(*) – denotes items that are options

NOTES ABOUT THE INGREDIENTS USED AND SUBSTITUTIONS

- The chia seeds or ground flax are optional but provide some much needed omega-3 fats and fiber. I prefer the chia seeds because they make the oatmeal even more pudding like. If you want to gain weight I would increase this to 2 or 3 Tablespoons.
- In addition to adding flavor, the cinnamon will help to stabilize your blood sugar levels
- I use stevia (SweetLeaf for dry, Stevita for liquid) instead of sugar because sugar causes me pain, due to its inflammatory nature. I find when I have too much sugar I can hardly move the day after so I always limit the quantity and I prefer coconut sugar (lower glycemic and less refined than table sugar), raw honey (has antioxidant and antimicrobial properties) or maple syrup (contains minerals and antioxidants).
- You can substitute some type of milk for the almond butter/water combo but remember cow's milk is pretty high in protein and may interfere with your drugs.
- I use coconut oil because it contains fatty acids that are good for the brain, provides energy and can even kill some bacteria, fungi and viruses. It's supposed to help you lose weight but it contains a lot of calories so if you're trying to gain weight you can add more – just reduce the water by an equal amount.
- Blueberries add a lot of flavor and fiber and they have antioxidant and anti-inflammatory properties.
- Avoid extracts with propylene glycol if possible –it's basically anti-free

THE HUMOROUS SIDE OF PD

Hospitals

By Judith Iovanna



I was recently hospitalized and I live to write about my adventure. I found myself just overwhelmed with all that happens in the hospital and how quickly you need to adjust to the pace.

Upon arriving at the hospital I was asked questions as to why I was there. I explained my problem and that I had PD when my husband entered the room the questions were directed toward him. "Hello! I can answer the questions. PD doesn't make me dumb." Shortly after this event I realized that the staff was shouting at me. "Hello again, I can hear "PD doesn't make me deaf.

The doctor decided to do an eye exam. I sat there looking at the chart and I was reading the letters rapidly and as the letters got smaller, I was reveling at my good eyesight until one of my friends, a nurse, interrupted my revelry stating "You need to cover one eye!" So much for



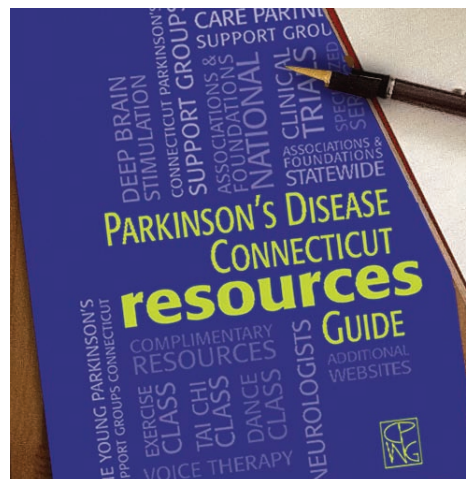
my super eyesight!

When it was decided to admit me, a lady came into the room with more questions. It was when she asked this question I could not resist this answer. Going through a list of questions she asked "Do you have your own teeth" I replied "No I borrowed these from someone else. (It was funny then!)

During my stay at the hospital this event was most my most dramatic. I was eating lunch and a piece of meat seemed to get stuck in my throat. I could not swallow. I panicked and waved to nurse and yelled "I am choking on the meat. Get me some help." She calmly replied "You are not choking because you are able to talk." That was it. I began to gag and told her to call a code or do Heimlich on me. I am sinking with the ship, call 911 throughout this ordeal, the nurse maintained her composure and calmly said again "You can't be choking because you are talking." Finally I was able to swallow the offending meat. I meekly offered an apology and hid under the covers. When the next meal was served that evening, my menu had a large blue stripe that highlighted this sentence "cut all meat!!" It was quite an adventure.

PARKINSON'S DISEASE CONNECTICUT resources GUIDE

UPDATED!!



Learn about a variety of state, local and federal resources in the Parkinson's Disease Resources Guide.

You can see it on our [website, cpwg.org](http://www.cpwg.org). Just click on Resources Guide at the top of Home Page and learn about a variety of state, local and federal resources.



**CONNECTICUT
PARKINSON'S
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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

July 16– **NO MEETING THIS MONTH**
Join us at the 3rd MADPA Symposium University of
Saint Joseph, West Hartford (see page #5 for details).

August 20 – Apokyn PD rescue drug Shelia Thurlow,
Circle of Care Nurse, Dr. J. Antonelle de Marcaida

September 17– Tom Cushing – Tai Chi for Parkinson's

October 15 – The Baldwins, September 2016 4th
World Parkinson Congress, Portland, OR Report

Events:

Save the Date for the 2016 World Parkinson Con-
gress, September 20-23, 2016 in Portland, Or See
page 5 daries

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/>.

TAPSG Walk in the Woods, September 18, 2016
White Memorial conservation Center, Litchfield
<http://walkforpd.org/>

Partners in Parkinson's NYC Oct. 1 Providing infor-
mation, resources and opportunities to meet patients,
caregivers and clinicians. [https://www.partnersin-
parkinsons.org/lattend-an-event](https://www.partnersin-parkinsons.org/lattend-an-event)