
WINTER 2011

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CPWG ANNUAL REPORT 2010

By Jackie Dorwin

This time of year, after the deluge of holiday catalogs, comes the onslaught of annual reports. I have often thought of the people who have to write these reports and pity them for having such a boring job to do. Well, here I am, keyboard at hand, writing an annual report. Considering the year our group has had I think a brief piece is warranted if for no other reason than to tell you that CPWG is alive and doing well. We are quite a group.

Parkinson's disease has been a difficult addition to our lives, but individually and collectively we are learning to handle it with grace, persistence, and a touch of humor.

CPWG continues to refine its participation in the Connecticut Parkinson community. Our efforts and activities are focused on education and support. A few times our focus has been blurred a bit, but in the process we learned more about our group. We have produced two fine conferences in the past several years which were well-attended and well-regarded. We did an excellent job, but it took too much time and energy away from our primary programs. It is through smaller information sessions and presentations to local groups that we can serve the PD community most effectively. As I sit here writing this, our calendar for the

next 3 months has 3 confirmed commitments on it—one is an 'encore' presentation at a shoreline VNA; the second will be an Information Session specifically for Home Health Aides, and the third is the West Haven Veteran's Administration 2011 PD Symposium where we have been invited to be on their panel. We have other 'dates' in the works, but they are not confirmed.

The mainstays of CPWG continue to be our newsletter which is published 4 times a year and our monthly meetings. Opportunities to gather information and receive support are abundantly available in both venues. Middlesex Hospital in Middletown has been our home for several years and we are grateful to the hospital administration for allowing us the use of their facilities. The meetings are open to anyone with an interest in PD, and we have benefitted once again from a variety of speakers and topics which last year included massage therapy, yoga, chiropractic, and reiki as possible therapies for PD; police awareness of PD symptoms; a session on care-partnering, and a meeting devoted to parlor games and brain exercises. Our popular 'open mike' meetings remain a welcome tradition. Discussion has always been a vital component of every meeting, whether it is before, during, or after the scheduled meeting hours. A separate room is available for Carepartner breakout sessions. What happens in their group stays in their group. Attendance at our meetings has perked up this year, and we are now averaging 40 or so people. That is a workable number for us—not too large and not too small, although we have had to borrow chairs

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EDITORIAL

EDITOR'S NOTE:

We wish to thank Bob Mandelkern for the following letter in response to the interview with Ann Williams in our last issue. Although the article was written to offer insights into her husband's choice of stem cell transplant as treatment for PD, it was not intended to endorse that path. However, we were remiss in including an editorial note indicating a 75% success rate for the procedure and in not presenting some of the serious concerns outlined in Bob's letter.

LETTERS TO THE EDITOR:

I write as a Parkinsons patient for the past 10 years; as Connecticut State Co-Coordinator of the Parkinsons Action Network; and as a state appointed official to the Connecticut Stem Cell Research Advisory Committee, to offer another point of view on the interview with Ann Williams in the Fall 2010 CPWG News.

It is understandable that PD patients, given the chronic nature of the disease and the fact that there are no known therapies to halt the degenerative aspects would turn to unproven, unverified, un-peer reviewed treatments from overseas clinics that offer treatment for a variety of chronic and degenerative diseases.

I suggest to PD sufferers who are considering stem cell treatment to look at the website of the International Society for Stem Cell Research, an organization of over 3,000 recognized accredited and established stem cell researchers, at <http://www.closerlookatstemcells.org/> where one can find the top 10 things known about stem cell treatment. This website will certainly induce caution about following any unproven treatments that are being offered by many overseas clinics that promise therapeutic relief from disease. These clinics offer no studies, no trials, no statistics and no peer review work that would recommend them to patients.

In reference to the specific Ann Williams interview, it is unfortunate that there is the assertion by the editor of the claim of 75% success in treatment from the Xcell Center in Cologne, Germany. This claim is apparently based on the word of the center itself as there are no studies, no controls and no data to evaluate this claim from any other source.

The projection that this procedure if accepted in the US would cost \$35 to \$50,000 is very problematical. The very first clinical trial in the US using embryonic stem cells has just been undertaken by the Geron Corp. with FDA approval, for spinal chord injuries. This is a preliminary clinical trial to test the safety of the drug over a small number of subjects.

The Xcell Center in Cologne that was visited by Dave and Ann Williams is the most well known overseas clinic offering stem cell treatment. This center actively advertises and maintains representatives in the US to market their treatment. My understanding is that at the June 2010 International Society for Stem Cell Research meeting it was noted that the Cologne clinic was likely to be shut down due to a conflict with European Union laws concerning unproven therapies.

There is much more to be said on the subject, but I would hope that you would print this other point of view for consideration by your readers.

*Very truly yours,
Bob Mandelkern
West Hartford, CT*

Congratulations on a wonderful news letter. I think it was one of your best and will be hard to top. It had it all, but most of all it had the human touch. We especially liked the article by Judith Iovanna, on the Humorous side of Parkinson's. It still has us laughing as well as our family members and friends. Judith showed that we should be able to laugh with the Parkinson's patient and see the funny side of the problems he or she is facing. We recently saw Michael J. Fox at UConn, he was great, but his stories did not top Judith's. We also love to read the interviews and the updates on procedures others in the group have had. Reading about the latest drug trials and clinical trials is important, most important is the stories about others with the illness and how they are, or have handled it.

*Thank you for a most enjoyable read.
Ken and Aggie Schulte
Suffield, CT*

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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 any 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.

BIOMARKER BASICS

Courtesy of the MJFF Newsletter, with edits by Danna Jennings, MD, of IND

What is a biomarker?

A biomarker is any measurable physical characteristic or process that can be used to objectively track and measure the presence and/or progression of disease. For Parkinson's disease, it could be a molecule found in bodily fluids such as blood or cerebrospinal fluid, a substance or process in the brain visible with advanced neuroimaging techniques, or even a change in a bodily function such as the sense of smell. It must be objective and measurable through a standardized lab test, imaging procedure or behavioral assessment.

Isn't a biomarker basically a gene?

No — in fact, a biomarker does not have to be a gene or genetic mutation. (Remember, it's possible to have one or more genetic irregularities linked to PD but never get the disease.) Genetic research can lead scientists to certain biomarker candidates, but many other physical and cellular characteristics are valid as possible biomarkers if they are measurable and provide an accurate window into disease risk, presence or progression.

Are there any known biomarkers of PD?

While the field has not yet uncovered any confirmed biomarkers of Parkinson's disease, several promising candidates have emerged in the past decade. For example, research has now established that levels of the protein alpha-synuclein are altered in people with Parkinson's. Studies, including the Parkinson's Disease Progression Marker Initiative (PPMI) will now serve as a testing ground to validate these promising leads in a well-characterized, diverse population of people with and without Parkinson's over time. This collaboration will help increase the pace of biomarker validation and clinical testing as well as accelerate the pace of discovery.

What is the PPMI Study?

The Parkinson's Progression Markers Initiative (PPMI) is an observational research study to identify biomarkers of Parkinson's disease (PD) progression. A biomarker is a substance or characteristic in our bodies that is associated with the presence of disease, or that changes over time in a way that can be linked to the progression of disease. An observational study means that study participants will undergo numerous tests and assessments of bodily processes related to PD, but will not receive an experimental drug or treatment. This study will use a combination of imaging techniques, collection of blood, urine, and spinal fluid, and clinical tests. The information gathered from these procedures is critical to the future development of new and better treatments for Parkinson's disease. PPMI is the first clinical study to as-

semble a population of sufficient size to collect this information, draw meaningful scientific conclusions over time, and try to develop better ways to measure the progression of PD

The study will be conducted in the United States and Europe. It is expected to take about five years. It is being sponsored by The Michael J. Fox Foundation for Parkinson's Research and will be made possible through the efforts of agencies interested in PD drug development. The study team includes many clinicians and scientists who conduct research in Parkinson's disease. It will be led by principal investigator Ken Marek, MD, President and Senior Scientist of the Institute for Neurodegenerative Disease, New Haven, Connecticut. For more information about the study please contact Barbara Fussell, RN, at (800) 401-6067 or bfussell@indd.org.

They're the most critical piece of the drug development puzzle that you've never heard of. Brush up on biomarkers and why they matter so much to Parkinson's drug development.

How and where will PPMI researchers look for PD biomarkers?

PPMI will focus on identifying three types of biomarkers:

- Clinical biomarkers including cognitive activities such as thinking and memory, mood and heart rate will be tracked and measured over time.
- Imaging biomarkers use very sensitive neuroimaging tools called PET or SPECT cameras to let researchers "see" and track changes in the brain of a Parkinson's patient.
- Biological biomarkers are chemicals in body fluids including urine, blood and cerebrospinal fluid. PPMI will analyze cerebrospinal fluid especially closely. This is the fluid that bathes the brain. Because of its proximity to the primary organ affected in PD, it is expected to be a critical source of potential biomarkers.

Where can I learn more about biomarkers?

Check out www.michaeljfox.org/ppmi for in-depth analysis of biomarkers currently under investigations.

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INTERVIEW—ANDY WEATHERWAX

By Jeff Lincoln

Preface: Yes, Weatherwax is his real name and it is of Dutch derivation!

Jeff: I usually start out with a few questions to establish a baseline. First of all, how long has it been since you were diagnosed?

Andy: It has been about ten years. I was 39 years old. It's going on eleven now.

Jeff: What medicines are you taking?

Andy: I take Sinemet and Comptan (similar to Stalevo) and Azilect. Also I just started on Clozapine which helps me to focus. I take a very low dose before going to sleep. It takes the edge off the agitations of the day.

Jeff: What was the path that brought you to the realization that you have Parkinson's disease?

Andy: During the holidays, I loved cooking and in 2001, I did ALL the cooking, day in and day out. I loved cooking. My lower back was really hurting me and my left hand was slowing down. At the time, I had started a business doing digital marketing consulting, and I had to type a lot. My little finger on my left hand would rest upon the "a" key. I'd get long strings of "aaaaaa...". I went to the gym a lot and thought that maybe I'd pinched a nerve. One doctor who did lots of tests such as MRI, blood samples, etc., concluded that I should see a movement specialist. I scheduled an appointment and at the end of the interview, the movement specialist asked "What do you want to hear?" I said that I wanted to hear that I had a pinched nerve and that I'd be fine in a couple of months. Instead, he told me, "You have Parkinson's disease."

My wife and I went to a Mexican Restaurant that night. We were quiet. Parkinson's disease; this was the first time I had ever personally come across it, and said to my wife that "I certainly didn't see that one coming." The next morning I woke from a deep sleep and just started laughing because I realized that there was nothing to do about it; it was what it was.

Jeff: We know you now as a poet. Were you a poet then?

Andy: No. I didn't think of myself as a poet or a writer, but I was always creative and went to the Hart School of music for jazz trumpet. However, the day after I was diagnosed, I started writing. I was running my business, which was called "Brain Bug" [laughter]. Actually, the business was named long before I was diagnosed. Just one of those weird things. Anyway, I just started writing. Sometimes I'd write until I heard the birds in the morning, and then would say, "Holy cow another all-

nigher". My neurologist was interested and eventually wrote a book about writers and writer's block. What I was experiencing was called "Hypergraphia", the opposite of writer's block.

*the gift**

by Andy Weatherwax

*this is a gift
and I am ill with it*

*it bounces around my brain
slowly seizing my ability
to move
to speak
to think*

*this is a gift
I told my six year old son
not the type you wrap with a bow
not a gift you would wish upon anyone*

*there was a time when
my musings strayed to madness, thoughts to terror
there was a time I would blame the moon
for it's blurred reflection in turbulent waters*

*but gratitude's exquisite blossom now fills my heart
leaving fear no recourse
clarity returns
I can see the moon*

*this is a gift of understanding
of the suffering caused by illness, old age and death
this is a gift of compassion
that puts self-pity in the past
the future is now and now and now*

*I breathe
the clear sky above my head
the vegetable garden at my feet*

*this is a gift
and I am alive with it*

I showed my writings to my wife, Josa, and it gave her some insight into my day, so I made up a small pamphlet one holiday and gave it to my close family. At the time, I had sold the company for a dollar. After I was diagnosed, I started another company based on some ideas I had. I had an office in



Andy Weatherwax

Balanced Rocks-Block Island*

New York City and I gave a copy of my poems to a person there. At Christmas, I got a phone call from her thanking me for the poems and saying how much they had helped the two of them. So I started seriously compiling my writings although I was a very reluctant poet. It always seemed too lofty a title.

Jeff: What might you have done if not poetry?

Andy: Something creative. Whether balancing rocks, writing poetry or other creative activity.

Jeff: Did success in business allow you to write poetry?

Andy: I don't even know how I arrived here, but I am so grateful and blessed for this company I started after I made the one dollar. I contacted two former investors, great guys, and we started "Global Strategies". We had an epiphany about the impact of the digital age of marketing. The impact was far greater than anybody could have imagined. We worked with big companies and fundamentally changed the way they did marketing. The company took off when we landed IBM, MetLife, Yahoo and BP. After 3 years we had a stable of clients. The smallest client was MetLife which was 36th on the Fortune 100. And I was working out of my bedroom! We had to be doing something right. Before we came along, these companies would push products through TV. It was all about brand name awareness. Push marketing worked well when people had to get up and go somewhere to buy a car. Now I could search 5-6 dealerships, talk to people who own the car, research safety reports, find financing, and have the car delivered to my house and never even have to put on my pants. That's pull marketing. They will find you only if you have something out there that they want. While that seems simple, big companies had to change the whole way they talked to customers. Prior to this, everyone wanted to be the next Kleenex or Q-tip or Band Aid. After this, a company such as Castrol [ed.note: Castrol is not a customer of Andy's company] now has removed all references to motor oil on their website. If I want to change my oil in my car, I have to look for "liquid engineering" to find Castrol. They were willing to change the

way they market products. That's what our company does – it helps management change the way it markets.

Jeff: Are you still active in the company?

Andy: I keep tabs on the company quarterly. We sold the company for a nice chunk of money, and I got a percentage of that. I'm not sure exactly how it happened, but I made enough money to retire.

Jeff: How did you link up with the Michael J. Fox Foundation (MJFF)?

Andy: I started to attend their Research Roundtables. I think they really hit it out of the park with the way they go about fund raising and the way they go about leveraging that money.

Jeff: The things that you have been discussing all seem to involve high pressure, which some people with PD (PWP's) find hard to handle. How did you handle the pressure?

Andy: Well, I was starting not to be able to handle it. In the last job, I traveled 10,000 miles a year. It got to the point where I wasn't able to keep up; I wasn't able to focus.

Jeff: Did the companies you worked with know you had PD?

Andy: Yes, I was very up front with that and with Deep Brain Stimulation (DBS) which I underwent in 2007. My neurologist said that there were some clinical trials suggesting that early onset PWP'S (less than 60 years old) would benefit most from early DBS surgery, but I'm not the poster boy for DBS.

Jeff: Do you have any advice for other PWP's?

Andy: For me, I'm a practicing Buddhist. Over the years I have gotten more and more into it, and in a year I'll be a Sensei, but that's another story. My advice to PWP's is to do whatever you can through meditation to arrive at peace with reality as it is. Don't wake up every morning suffering with PD and saying "Shit, I still have it." There is enough real suffering. My advice is to accept that it is what it is. My wife says that my poetry is so sad, but for me it's a joy, sort of like coughing up a hair ball and gaining catharsis.

Jeff: Andy, thank you for spending time with me and sharing your poetry and rock balancing photography with our readership. I look forward to the publication of your poetry book. Maybe we could balance some rocks this spring...?

Link to Andy's videos on youtube:
<http://www.youtube.com/user/brainbugAndy>.

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HAVING FUN WITH PD

By Kendra Hough, RN, PWP

That may sound like an oxymoron...but take a peek at what I mean. With a diagnosis of PD hovering over me in my recovery stages of cervical neck fusion surgery, I made the hard decision to seek early retirement from my labor and delivery nurse job at Middlesex Hospital in 2007. Being a single breadwinner the ideas of doing without my dependable income and all the frightful cobra costs really initially scared me a lot...not to speak of the thought of PD! However I easily became used to not having to drive in to work at 10 p.m. at night for that grueling shift...especially in inclement weather. And I never did figure out how much of sleep upset was due to returning to the norm of sleeping nights and being awake days, which I had not done for decades. And, despite my subsequent diagnosis with PD, I began having more fun than I had in years.

The first year I went to Ireland...alone...on a small tour with an off-the-beaten-path type provider and saw loads of sacred sites and similar things that I adore. Then I turned around and did it again...same tour provider...this time to Northern Ireland. I noticed I struggled a bit more, was a slow walker by this time but was fighting Lyme disease at the time. Then on to a wonderful small ship cruise called "Between Two Seas." We, meaning a small group of about 90-100 people on a small ship, travelled along Panama, through the Panama Canal and along the coast of Costa Rica exploring the Costa Rican parks. I did not participate in everything, but enough to make it worthwhile...again as a solo traveler, but made to feel wonderfully at home by the crew and my shipmates. As a matter of fact, the profound impact of PD on my life began to be revealed on that tour. I had not known that strong emotion (good or bad) would exacerbate the symptoms of PD...and was quite shocked to find myself not just visibly trembling but shaking violently as I delivered a commendation to the crew upon recognition of their excellent performance and care. Even with this thought provoking occurrence, my trip was fun. As an aside, I find that the presence of handsome men also sometimes make me shake violently. PD! It gives up your secrets!!!

Subsequent planning for further trips has been put on hold...not because of PD but because of a changing world view of Americans abroad and perhaps more pragmatically as finding myself the primary caretaker for a diabetic cat...a brat cat...on insulin...did I forget the matter of cash?

The above intermission in my adventures abroad has necessitated a re-evaluation of "fun things to do in Connecticut".

I decided to rethink Connecticut and pretend I was a visitor here looking for fun things to do...things I could do. I am not sure it was first, but somehow I found Meetup.com, which brings people with common interests together in a safe way...interests ranging from entrepreneurship, to dog walking to (YAY) scrabble. I have been playing scrabble every week with a small group for three years...a social interaction that I cherish. I also saw an ad regarding my local library desiring volunteers for their used bookstore housed at their senior center. Although it is "just" receiving, pricing and shelving books, it not only gives me first dibs on great, cheap books, it has put me in contact with some lovely people. For a solo PWP this is both fun and important for wellbeing. Besides, I discovered that I love to be surrounded by books!!

...the profound impact of PD on my life began to be revealed on that tour. I had not known that strong emotion (good or bad) would exacerbate the symptoms of PD

Additionally, I was exposed to the world of hand drumming through attendance at a small hand drumming circle in East Haddam in a yurt. Well, that small event has changed my life. Perhaps it is the compulsive side effects of Mirapex, but perhaps not. I am hooked on hand drumming despite my tremor and like the mailman storming through all kinds of weather...not much keeps me from my favorite drum circles. I am not a musician in any way, shape or form...but within the charming underground of hand-drumming circles there is room for expression by the amateur and that in itself brings a wonderful feeling of participation and spiritual peace. There are books written on the healing nature of drums...some of which specifically mention neuro-degenerative disorders. I have explored drum circles all over the state and have initiated a newsletter about them...which is in pause mode at present, but one can see how one thing leads to another. Having these three great things to be involved in is especially beneficial for a lifelong shy PWP with limited outlets for social contact...remember I slept days and worked nights for over 20 years.

Am I having fun with PD, yes I am!!!

on several occasions. Our blockbuster event of 2010 was the fundraiser in September, *Movin' and Groovin' to Stop the Shakin'*. Our hearts and souls went into this buffet-auction-dance-entertainment happenin' that had something for everyone. Close to \$10,000 was added to our Treasury. These funds raised will be used to support CPWG's programs.

One of these programs started out as a suggestion for therapy based on the techniques developed by the Mark Morris Dance Studio of New York. We currently have weekly "Dance for Parkinson's" classes that meet in New London and Middletown. Along the way these classes have loosened up our muscles and stretched our imaginations, but CPWG does not want to run the program in perpetuity. Administering the program was blurring our focus and sapping our energy. We are now actively in discussions with a Connecticut dance school to take over the classes.

A word about our finances: we're solvent, in the black and doing just fine. CPWG does not charge for our meetings, our literature, our programs, our classes. The money needed to successfully run our group comes from donations to the basket on the Welcome Table, grants, memorial contributions, No-Neckties cash gifts, and YOU. Your generosity is beyond compare, and we are most grateful.

The CPWG newsletter underwent some staffing changes and a make-over in 2010. Early response has been favorable as we continue to seek out and provide articles of merit and interviews of substance. Over 400 readers receive a copy free-of-charge and they are encouraged to pass it along. The website is also gaining acceptance as a useful tool of communication. As more of our community becomes computer literate, it will enable us to reach a wider audience.

There is so much more to talk about, but space and time are tugging at the keyboard to close down for this year. I feel like this is a condensed article, giving only the highlights of only a portion of our work with PD. Parkinson's disease has been a difficult addition to our lives, but individually and collectively we are learning to handle it with grace, persistence, and a touch of humor. With the help of other participants in the group, we seem to have found a way to lighten the load. Come to a meeting, read and respond to our newsletter, call us and chat for a while and you will find that CPWG really is quite a group.

BREAKING NEWS:

Potential U.S. Supply Shortage of SINEMET® and SINEMET CR®

Merck & Co. Inc. has informed the Parkinson's disease community that in early 2011 there may be a potential temporary supply shortage in the U.S. for SINEMET® (carbidopa-levodopa) and SINEMET CR® (carbidopa-levodopa controlled release tablets).

While there is currently no shortage, it is advisable to speak with your health care provider about appropriate steps should a shortage occur. Your health care provider can give you relevant information about potential short-term alternative therapies, including the availability of alternative generic equivalents.

The FDA has shown generic SINEMET® to be effective against the symptoms of Parkinson's disease, but dosing may need to be slightly adjusted due to differences in manufacturing and formulation. Should you need to temporarily switch to a generic version of SINEMET®, be aware that some people may experience a change in how the medication works. If you do experience a change, contact your health care provider who may prescribe a different dose or timing regimen.

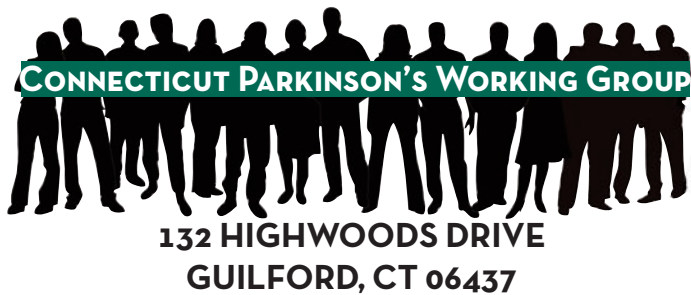
Patients, caregivers and health care professionals in the U.S. who have more questions about the availability of SINEMET® can contact the Merck National Service Center at 1-800-NSC-MERCK.

NPF* is committed to keeping you informed of developments on this issue. We will alert you if we get any more information about either a shortage developing or the crisis being averted. If you are informed by your doctor or pharmacist that SINEMET® is not available in your area, please contact us at 1-800-473-4636 or helpline@parkinson.org. If you have any questions, Dr. Okun is prepared to address issues about the shortage and generic substitution on our Ask the Doc online discussion forum.

*Information provided by the National Parkinson Foundation

REMEMBER:

April is Parkinson's Awareness Month. In Connecticut, there are over 20 PD Support Groups. For additional information on these groups and their programs, contact Donna Diaz at the American Parkinson Disease Association office in New Haven at 203-789-3936.



CALENDAR

CPWG ACTIVITIES:

CPWG Regular 3rd-Saturday-of-the-Month Meetings, 10:00 a.m.-Noon. Middlesex Hospital, Middletown, CT

February 19—Parlor Games and Brain Exercises. Good therapy for PWP. Many games and word puzzles will be available but you are welcome to bring your own to share.

March 19—Sharon Johnson, RD, Registered Dietitian; Practicing in Guilford for 25 years; recently did extensive research on PD and nutrition. Your questions and participation are encouraged.

April 16—Program to be determined.

For additional information, call Tom Sullivan (860-343-8278) or Jackie Dorwin (203-453-2655).

PARKINSON'S DISEASE FOUNDATION:

Live Online Seminars, 1 – 2 p.m.

February 8—Physical Therapy and PD: What you need to know

March 22—PD & Cognition

April 12—What's in the PD Pipeline?

For additional information go online to <http://pdf.org>

OTHER:

March 26—Sat., 10:00 a.m.- 12:30 p.m., "Parkinson's Disease Educational Forum", Sullivan Senior Center, 88 Albert St., Torrington, CT. For more info/register: 1-877-282-7328/ddiaz@srhs.org.

April 2—Sat., 8:00 a.m.-1:00 p.m. Dept. of Veterans Affairs: 2011 PD Symposium, Patient Centered Care: Movement and Beyond. Free annual symposium, (CPWG participating in panel) seating limited on first come basis. For additional information or to register, call Dept. of Neurology at 203-932-5711 ext.4724.

April 16—Sat., 17th Parkinson's Unity Walk, 72nd St. Bandshell, Central Park, NYC. Registration begins at 7:30 a.m.—Walk starts at 9:45 a.m.