



Newsletter of the Connecticut Parkinson's Working Group

Summer, 2010

CPWG TO HOST

MOVIN' AND GROOVIN'

As this newsletter goes to press, plans are well underway for an exciting evening of dining, dancing, and an auction of many "can't live without" items. All proceeds are to benefit the activities of CPWG. Board Member Dr. Toni de Marcaida and her committee have been busy setting the date for Sunday, September 19th, from 4 to 8 pm, at the Tango Italiano Restaurant in Glastonbury, CT. The buffet will feature traditional Italian food with a "touch of Argentinian flavors". There will be vegetarian and gluten-free selections included in the menu and a cash bar will be available throughout the evening.

Also on the program will be a group of instructors from the Fred Astaire Dance Studio of Glastonbury to entertain us with a show of their talents and to offer the guests an opportunity to dance with professionals. An added attraction will be an auction of many enticing goods and services that will surely draw some enthusiastic bidding!

Hurry though, seating is limited and the response has been brisk. The box to the right has reservation information and contact numbers for donations of auction items.

This is an evening you will not want to miss!

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The Connecticut Parkinson's Working Group presents

Movin' and Groovin' to Stop the Shakin'

A Benefit Event

TANGO RESTAURANT & BAR
2935 Main St.
Glastonbury, CT

September 19, 2010
4 - 8 pm

Dinner - Dance - Auction
featuring the Fred Astaire Dance Studio
of Glastonbury

Reservations: \$25 per person

Make check payable to CPWG

Send to: Steve Holahan

20 Jennifer's Way

Rocky Hill, CT 06067

To contribute auction items or services

Call: Tom or Pat at 860-343-8278 or

Judy at 203-237-4368

Editorial Staff
Interim Newsletter Committee

It is with the utmost regret that the Board of CPWG recently accepted the resignation of Stan Wertheimer as Editor of this Newsletter (NL). His dedication to bringing “all the news that’s fit to print” to the PD Community has left a large footprint for us to fill. This change of watch, however, has also caused us to reflect on the future direction of the NL. What types of articles? How frequently to publish? How to engage our readership and to get feedback from them? To address these questions and to get the NL up and running again, three members of the Board have volunteered to serve as an interim editorial committee. We would welcome participation from any and all who might like to help. We especially will appreciate hearing from you with reactions to specific articles, suggestions for future topics, or comments that you wish to share with other PWP. To this end, we are establishing a **Letters to the Editor** column and hope to see it become a vital part of this NL.

Interim Committee: Toni deMarcaida, MD
Steve Holahan
Debbie Weinstein

Letters to the Editor

Dancing with Parkinson’s. Thanks to CPWG.

Fred Astaire I’m not. And the only thing I have in common with Gene Kelly is that I can sing while getting wet. When I was diagnosed with Parkinson’s seven years ago, after the usual denial and depression stage, I vowed that the illness would not rob me of my sense of humor or my love of dance and music. Thanks to a wonderful growing movement in this country of dancing with Parkinson’s, I can still move to the music! Thanks to CPWG we have a dance program in Middletown. Our teacher, Laura, is wonderful. She knows about Parkinson’s, yet is no-nonsense as she makes you try and try again. And isn’t it strange for someone who has such trouble getting in and out of the car, once the music starts I can move so much better.

Sure, sometimes it’s hard, but what great things in life aren’t? For 75 minutes a week, and boy do I look forward to that, I leave my PD outside and go with the flow. Laura blends great music, classical, jazz, Broadway tunes, you name it, to our session. Being geared to people with Parkinson’s, although it’s totally enjoyable it does make you work. PD has taken a few joys from me, music and dance it can’t touch. And let’s not forget the wonderful camaraderie with your fellow PWPs. We are all in the same boat, so let’s turn the music on and dance. No one said we had to be great—as a wise man once said, “showing up is 90% of the work.” I wouldn’t miss my dancing with Parkinson’s time for the world. I highly recommend it.

by Jeff LaGrange



We are a family....

We are a family....we are the face of love. These are words from “The Face of God”, a song that I end the class with each week. In this first year, the CPWG class in New London has grown into a family. Yet, unlike many families, we don’t fight, we don’t take sides, we don’t tattle, we just **dance**. I know that studies have shown improved mobility and ease with the regular attendance of dance classes. But just as important are the social and emotional effects of a group of people coming together on a regular basis and sharing their humanity. I see participants arrive to class feeling low, shuffling, heads downcast. By the time they leave, they are wearing smiles on their faces and walking with a lightness that didn’t exist before they entered. They have been lifted physically and emotionally. That is the beauty of this dance program. We are united, we are supported, we dance, we laugh, we sing, we cry. We are a family.

by Rachel Balaban
Dance Co-ordinator for CPWG Dance Program

Interview with Jeff Lincoln

by Jackie Dorwin

He seems to be everywhere – testing the microphones before our meetings, taking photographs, interviewing interesting individuals, at the Post Office buying postcard stamps, at my house fixing my computer, driving up to Portland for a few more holes of golf, stretching his muscles at exercise class, giving presentations about PD to the local VNA, and then he's on his way to dance class in Middletown. And that's only part of it. Jeff Lincoln has been an 'active' member of CPWG since its re-invention in 2001, and we thought it was about time he was interviewed for this newsletter.

Jackie: The tables are turned, the microphone is adjusted, and this interview has been a long time coming. Would you get us started by telling us your background, where you were born and raised, and where you went to school?

Jeff: Sure. I was born in West Hartford, CT and grew up there until I went away in the Army. I went to college in Wesleyan University in Middletown, CT and have a degree in Bachelor of Arts and a degree in Zoology/Biology. I got involved in various things throughout the years, most of them technical because I like technical stuff.

Jackie: And you went in the Army before you went to college?

Jeff: No, after I went to college. When I was a senior and I got my notice that said 'Greetings,' I didn't waste any time. I enlisted in 1969 and mainly taught electronics, never went overseas, never went to Viet Nam, and succeeded in staying in New Mexico for about 2 years.

Jackie: After you were in the Army, what did you do?

Jeff: I worked for 8 years for Picker Medical, building and testing ultrasound scanners. If you were scanned at that time for any kind of body scanning, it was one of our machines. After that I went to a place called Zygo and that was a high tech manufacturer of laser gauge machines. For the last 19 years I worked for Yale University, first in auditing and then in information technologies.

Jackie: Tell me how you came to be diagnosed with PD.

Jeff: In the year 2000, the doctor thought I had a small set of strokes. He sent me for a CAT scan and to physical therapy. Three months into it, the physical therapist looked at me and said "Jeff, you don't present as a stroke victim. There is something else going on. Go find out what it is." My psychiatrist said, "Wouldn't you like to find out if you have Parkinson's?" I said that I don't really want to know and he said, "You're an idiot! You'll feel much better after you know." I was referred to IND (Institute for Neurodegenerative Disorders), where I was diagnosed by Danna Jennings in the summer of 2001 as having Parkinson's.

Jackie: What has that done to your life?

Jeff: Changed everything. Actually it hasn't changed anything that makes a difference.

Jackie: Like what?

Jeff: Well, I still ride a bicycle. I still read books and do things. I still do electronics and computers and that kind of stuff. The major thing in life is that you have to live off pills in intervals of time. It makes you think about having the disease maybe a hundred times a day when you do little things.

Jackie: You can't get away from it, can you?

Jeff: No, you can't get away from it. You can maybe escape from it for the slightest bit of time. The day I was diagnosed I signed up for my first clinical trial.

Jackie: How many clinical trials have you done?

Jeff: Oh, probably a dozen.

Jackie: How many pills have you taken?

Jeff: Thousands. The GPF 1485 was an agent with a 3-year clinical trial and I took 16,000 pills just for that.

Jackie: What made you sign up for so many clinical trials?

Jeff: I am not exactly sure. People who won't sign up mystify me, but the fact that anything to move the disease forward and the chance to get a new drug motivates me.

Jackie: I hear your golf game is doing pretty well and you always have your golf clubs in your car.

Jeff: Oh, yes, it's a good past-time with fellowship and people getting outdoors and walking around. If you can hit this ridiculously small ball into this ridiculously small hole then you are much better off.

Jackie: Have you tailored anything to fit your Parkinson's disease?

Jeff: I have modified everything I could to make things easier. I have a rope with a bar that I use to get out of bed in the morning. I have canes around the house. This belt that I'm wearing right here is because I didn't want to put my keys in my pocket because they're too hard to get out once you sit in the car. So I put a carabineer around of the outside of this pack and now my keys are hanging here.

Jackie: How has your family adjusted to your diagnosis of Parkinson's?

Jeff: Everyone is very supportive. Pam is there when I need her; isn't there when I don't need her. She's good at knowing when to do things. Jon and Catherine have been great, and the 5 grandchildren are too young to know that things could be different.

Jackie: Do you look down the road to the time when you can't manage by yourself? How do you feel about that?

Jeff: I don't think a lot about it. It will come in small steps. The first person that I interviewed for CPWG taught me the 'Four A's' of Parkinson's — adjust, align, accommodate, but don't abandon anything if it is important.

Jackie: You also have compiled a list of 53 symptoms of PD.

Jeff: Yes, that was a fun experiment. I said to myself, "What are the symptoms of either the types of medication or the disease?" I started asking others and stopped at 50.

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What's Shakin' in PD Research?

*Danna Jennings, MD and David Russell, MD PhD
Institute for Neurodegenerative Disorders, New Haven*

This is an exciting time in Parkinson disease research. We are on the cusp of identifying changes that occur before the onset of symptoms and research has advanced to the point that halting the progression of PD, and even preventing the onset of symptoms, are considered realistic goals. While an important goal is to prevent the onset of symptoms, researchers also continue to make great strides in developing more effective treatments for the symptoms of PD. In this article we will review the two basic types of research trials and provide information about some of the trials actively being completed locally.

Clinical trials of experimental therapy

A variety of new drug treatments for both early and advanced disease are currently in clinical trials for PD. Clinical trials are important in establishing the safety and defining the benefit of a particular therapy. These studies often involve randomization (or unbiased assignment) into a given treatment or non-treatment (placebo) group. Subjects are selected on the basis of a number of factors including disease severity and current medications. Clinical trials may last from weeks to many months and may involve frequent contact with investigators. Some of the current clinical trials involving experimental therapies include:

Studies involving agents with neuroprotective potential: The research program at IND and others across the country are part of an ongoing study to identify treatments which may slow the progression of PD. Since 2002, we have participated in the “National Institute of Health Exploratory Trials in PD” or “NET-PD.” This is a set of clinical studies to evaluate the most promising agents selected from initial trials. The most recent, NET-ZONE, is recruiting patients treated with MAO-b inhibitors (Azilect, Eldepryl). The QE3 study is aimed at evaluating the effect of a special formulation of Coenzyme Q10 on the progression of PD. The SURE-PD is a study looking into whether inosine (another nutritional supplement) may reduce the rate of progression of PD by elevating the urate (a.k.a. uric acid) levels. This study is enrolling individuals with early PD that are untreated and will soon allow treatment with Azilect, too. STEADY-PD is exploring a lead from the laboratory that the blood pressure medicine, Dynacirc, may also slow PD symptom progression.

As you can see, this is a time rich in evaluating prospects for potentially disease-slowing medications. While these may eventually help people with Parkinson's in all stages of the illness, they need to be studied prior to initiation of significant symptomatic treatments. So, be sure to alert people who have recently been diagnosed with PD or suspect that they may have it.

Studies involving agents with the potential to improve PD symptoms: There is a tremendous amount of interest in developing treatments that are not directly “dopaminergic”, in hope of better treating all symptoms or avoiding the development of “dopaminergic complications”. For instance, a member of a new generation of MAO-b inhibitors, safinamide, is being evaluated in individuals with early stages of PD who are being treated with dopamine agonists (Mirapex or Requip). In addition, another safinamide trial is looking at people in later stages of PD who have motor fluctuations, i.e have greater than 1-1/2 hours of “off time” each day. The hope is that this medication will improve the symptoms of PD and decrease off time in those with periods of wearing off from their medications. This study is also investigating whether this drug can improve cognition and/or mood in PD.

Another study is investigating an “adrenergic” drug, preladenant, in people with early PD who are not yet treated with dopaminergic medications. We are hopeful this approach will be effective while also averting some dopaminergic complications.

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Biomarker and observational studies

The second type of research seeks to improve our understanding of PD. Biomarkers for PD are measurable characteristics that can reveal whether the disease is developing or progressing, such as biochemical abnormalities or changes seen with specialized imaging. Such biomarkers could help detect the disease before symptoms appear, improve diagnosis of the disease, or potentially provide a window to the cause of PD or its progression. They can also play a role in evaluating whether specific medications or therapy have an effect on the course of the disease. Some of the most promising biomarkers for PD are measured by specialized brain imaging including SPECT and PET. Other potential biomarkers for PD include alterations in blood proteins or products of metabolism and gene expression.

Observational studies often involve biomarker assessments in addition to surveys or questionnaires to enable researchers to better understand specific aspects of PD. Examples of observational studies may be cognitive (thinking and memory) assessments, depression scales, sleep evaluations and motor examinations. Observational studies usually do not include an experimental medication and often involve a one-time visit or short period of participation.

Observational studies in early and pre-clinical PD: The PPMI study is an observational, multi-center study run by IND and sponsored by the Michael J Fox Foundation to assess progression of clinical features, imaging, and biologic biomarkers in PD patients compared to healthy controls (HC). The primary objective of this study is to identify clinical, imaging and biologic markers of PD progression for use in clinical trials of disease-modifying therapies. Individuals with early, untreated PD, as well as healthy controls, are eligible for participation.

Similarly, the PARS study, a study conducted by IND investigators, focuses on evaluating potential markers of pre-clinical PD and identifying strategies to determine who is at increased risk for later developing PD. The PARS study involves a two-staged approach using olfaction as a broad screening tool followed by dopamine transporter imaging as a more specific tool to identify individuals who may be at risk for developing PD. Individuals with no PD symptoms are eligible to participate.

Imaging markers of non-dopaminergic aspects of Parkinson disease: The goal of this group of studies is to evaluate imaging markers that may allow us to better understand the underlying causes of depression, cognitive changes, dyskinesias, and other features of PD. Understanding the neurochemical changes that occur in the brain through these imaging studies offers the potential for developing more effective therapies. Individuals with PD at a variety of stages are eligible for participation.

Genetics of Parkinson disease: There are several ongoing studies evaluating the role of genetics in PD. In an international study, individuals with the LRRK2 gene and their unaffected relatives are invited to undergo neurological evaluations, dopamine transporter imaging and provide a blood sample for genetic testing. Another genetic based study is the CORE-PD study, which aims to investigate genetic and environmental risk factors that increase susceptibility to the development of early-onset Parkinson's disease (developed at or before age 50).

A terrific resource to learn more about current PD research studies is available on www.PDtrials.org. If you are interested in receiving more information about research at IND, please contact Barbara Fussell at (203) 401-4345.

Jackie: You have many talents that you have donated to the Connecticut Parkinson's Working Group and we appreciate it. You help with the post cards and mailings, the newsletter and text set-up, taking pictures. Is there anything I am missing?

Jeff: I try to keep busy because if I don't stay busy, you get bored and if you get bored you get down. I would rather be tired and busy than be down.

Jackie: What kinds of physical things do you do, like the exercise class?

Jeff: I do the exercise class and the dance class. I play golf. They are helpful. With the exercise class I have realized, and the same with the dance class, is that it doesn't necessarily mean that when you leave you will be loose as a goose and be able to run around the parking lot. What it means is that for some time in your day you will have an easier time and you can forget you have a disease for an hour or so.

Jackie: How do you stay positive? Is it genetic?

Jeff: I think it is genetic. Most of my family has a positive attitude. My mom certainly has it and she is 92.

Jackie: How do you feel about CPWG?

Jeff: I think it is a wonderful thing, unlike any other support group I have ever seen or heard of. We have an active core of people. We mail them postcards before every meeting to let them know what's going on. I think some of our best meetings are the open mike when everyone comes and says whatever they want. I think it is great that the golfers have gotten a lot of publicity for the Parkinson's group.

Jackie: What other activities would you like to get involved in?

Jeff: I would like to start a group that plays Scrabble. I like to play but I haven't found people who like to play over a period of time.

Jackie: You have amended Susan Imke's 'Ten Commandments' for people with Parkinson's disease to include an eleventh commandment, "Thou shall hope without ceasing." That is a wonderful attitude. What do you see ahead in your life?

Jeff: I am not sure if I see a cure for Parkinson's. The definition of a cure is very strange because most people who have PD, if they were to stay the way they are, would consider themselves cured. They just don't want themselves to get any worse. But I think that it is a neurodegenerative disease. It will progress slowly but inevitably until we find a cure. I think there is a good chance that they will find a way to make life easier for us to bear. We have pretty good medicines now and one of the good things about this disease is that they have good medicines.

Jackie: What advice do you have for someone who has recently been diagnosed?

Jeff: I wouldn't give up hope. I wouldn't abandon anything. Talk to people before you abandon anything you like to do. Be reasonable. Don't use your PD-ness to mask laziness. It is very easy to say "I guess I won't go downtown to shop," because it is an easy thing to blame your disease. The other main thing is to keep a positive attitude towards the whole process. There are a lot of good people working on this.

Jackie: Jeff, thank you so much for sharing yourself with us.

Dance Class Update

As described in previous issues of the NL, the Dance for PD classes, based on the program designed by the Mark Morris Dance Group in NY, were introduced to CT last year by CPWG in two locations: Connecticut College in New London and Vinnie's Jump and Jive in Middletown. During this time, the classes have taken on personalities of their own under the two instructors, as apparent in the comments expressed by members of both in the Letters to the Editor column. The Middletown class has experienced a change in location and of instructor during this period but has still retained a loyal and enthusiastic following. The success of the two CPWG programs has led to still another class in New Haven sponsored by a local support group, Yale and Beyond.

Rachel Balaban, instructor of the New London class and overall co-ordinator for the CPWG classes, is often joined by L'Ana Burton as an assistant. With Laura Richling conducting the Middletown and New Haven classes, the three instructors bring commitment, talent, and enthusiasm to the Dance for PD Program and continue to engage in ongoing training with the Mark Morris Dance Group. Recently, David Leventhal, Program Manager for the Mark Morris Dance for PD, visited the New London class and lead it through a number of different movement series.

Anyone with PD is encouraged to join one of the ongoing classes. Caregivers and wheelchairs are welcome and no experience is necessary. As Rachel expresses it, "We love to dance and we want to share that joy with anyone who will dance with us." For questions, contact Rachel (401-261-7062) or Balaban.rachel@gmail.com.

(For location and contact information for all three classes, see next page)

CPWG CALENDAR OF EVENTS

CPWG IMPORTANT DATES

August 21st - CPWG Regular Meeting, 10:00 am
Middlesex Hospital, Middletown, CT

August 28th - CPWG Board Meeting, 10:00 am
Middlesex Hospital, Middletown, CT

Sept. 18th - CPWG Regular Meeting **Cancelled**

Sept. 19th - CPWG Dinner/Dance/Fundraiser

American Parkinson Disease Association (APDA)

Nov. 7-8, 2010 - New England Biennial PD Conference for people with PD and those who care about them.

Sturbridge Host Hotel, 366 Main St.
Sturbridge, MA

Featuring talks with national PD experts, workshops, vendors, and more.

For details: www.ctapda.org.

Dance Class Locations and Contact Information:

Connecticut College
2nd Floor Dance Studio, Crozier-Williams Building
270 Mohegan Ave.,
New London, CT 06320
Instructor: Rachel Balaban
Phone: 401.261.7062
Wednesdays 10:30-11:45

Middletown CT Senior Center
150 William St, Middletown, CT 06457
Instructor: Laura Richling
Phone: 203.675.2930
MON 1:30-2:45 PM

Neighborhood Music School
Sponsored by Yale Community and Beyond
Parkinsons' Support Group
100 Audubon St.
New Haven, CT 06510
Instructor: Laura Richling
Phone: 203.675.2930
MON 11:00AM-12:15PM through Aug. 9
Starting Sept: Tuesdays 11:00-12:15
(subject to change)

Parkinson's Disease Foundation Clinical Research Learning Institute

The Parkinson's Disease Foundation (PDF) is now accepting applications for the 2010 Clinical Research Learning Institute, to be held Oct. 21 - Oct. 23. This multi-day training provides PWP with the knowledge and skills to serve as advocates within the clinical research process, in order to improve the development of new treatments and find a cure for PD. Previous graduates have gone on to serve on clinical research review and advisory boards, work regularly with support groups, participate in professional and scientific meetings and write occasional articles.

This year's Learning Institute will be held in Florham Park, N.J., and is free of charge, with PDF assuming the costs for participant travel and accommodations.

If you are interested, an application can be downloaded from the PDF website at:
<http://www.pdf.org/crli>. Individuals without internet access may contact Director of National Programs Ronnie Todaro at (800)457-6676. Deadline for applying is Aug. 27, 2010.

Sept. 28 - Oct. 1, 2010 - 2nd World PD Congress

Glasgow, Scotland

The program will cover topics of interest to all members of the community.

[info@worldparkinsoncongress.org/](mailto:info@worldparkinsoncongress.org)

www.worldpdcongress.org.

212-923-4700

CONNECTICUT PARKINSON'S WORKING GROUP

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DISCLAIMER:

Articles in this newsletter are for information only.
Any question of treatment should be discussed with your physician.

Write your Representatives in Congress!

Senator Christopher Dodd
Russell Senate Office Building
Washington, D.C. 20510

Senator Joseph Lieberman
Hart Senate Office Building
Washington, D.C. 20510