

CPWG Newsletter Special Edition

Dance and PD in Connecticut

May 2009

This is a special issue of the newsletter devoted to PD and Dance. The major reason for this is a project that we at CPWG have taken on - perhaps the most ambitious since our inception in 2000. We are sponsoring classes in dance for PWP. This has the makings of an oxymoron - PWP can sometimes not walk, and now they are expected to dance -- and like it??! YOU BET! We will start our issue with an open letter by one of our resident curmudgeons Jeff Lincoln.

I COULD HAVE DANCED ALL NIGHT

An Open Letter to the PD COMMUNITY

Jeff Lincoln 5/18/2009

Well, maybe the title is a little exaggeration, but it sure captures the spirit of the dance classes at Vinnie's Jump 'n Jive. The dances are fun. The exercise is mild. The companionship is excellent, but I wonder if there has to be something more here, maybe even something profound at work.

One of the most difficult things about being a person with Parkinson's disease (PWP) is that we can never get very far from the disease. There are literally thousands of stimuli both in our bodies and outside of us to remind us that we are PWP's. I'm sure that non-PWP's see the same stimuli but don't have any reason to react as we do. To escape from the shackles of PD even for a short time is a large benefit.

During classes, I've seen this loss of body conscientiousness time and time again. I've seen a PWP with severe dyskinesias walking completely normally after a dance set. Another PWP came in a wheelchair. The first week she tried to march with the help of 2 others but managed only to go about a foot in a couple of minutes. Last week she marched with the help of one other and went about 30 feet. All this time she had the most beautiful smile. Something is going on here.

Another part of dancing is to perform synchronized movement to music. The music is the magic here. Exercise classes typically go through various routines to build strength increase range of motion, but not in a synchronized manner. In dancing to the music, PWP's find the ability to move in ways that they couldn't do without music. It's almost as if the music carries the dancer. It is truly a time to do things - new things.

The dance classes usually have large mirror walls. These amplify all of the other effects, because PWP's can see if they are doing the right things or if they are doing things right. It is easy to bend over while believing that you are standing straight, but not when confronted with your image in the mirror. Here the dance class leads to more normal posture because the PWP practice all week and then seeing how it works during class.

As a former card carrying skeptic, I'm now converted, but I wonder why the dance classes are only about ½ full. I understand that people are busy, even PWP's. It is a 45-minute drive to Middletown. The benefits I described above, may not be evident or significant. There are always more reasons not to do something than there are to try something. I believe that the benefits outweigh the costs (Time). All you have to do to prove this to yourself is to attend a class and watch people as they walk in and walk out about an hour later. I am not exaggerating when I say that we are saving PWP'S quality of life. Put on those dancing shoes.

This wonderful letter sets the tone we have about these classes - upbeat, optimistic, joyful. We want them to succeed for the benefits they can bring to the participants. We are starting two because we cannot support (read "fund") any more at this time. Our universal policy is that we never charge the PWP, or anybody else, for anything we do but we can only do it for part of a year. If you want to help, you know how to do so: send all support to Steve Holahan, 20 Jennifer's Way, Rocky Hill, CT 06067 That would give us time to seek major funding from PHARMA (the large pharmaceutical companies), foundations, and municipal and federal sources.

Now, read on to find out how we are doing all of this.

This piece was edited by Deb Weinstein on very short notice.

People with PD Discover the Joy of Dance By Rachel Cox, AARP February 20, 2009

Grace, the physical kind at least, is a quality not often ascribed to people with Parkinson's Disease (PD), a neurological disorder that gradually robs patients of the ability to perform even the most basic movements without great difficulty.

But on Tuesday afternoons in a spacious studio of the Maryland Youth Ballet in Bethesda, Anne Davis, diagnosed with PD eight years ago, recaptures a feeling she once knew well during a girlhood of horseback riding and ballet lessons. Urged on by choreographer and teacher Lucy Bowen McCauley, buoyed by the rhythms of familiar piano tunes, Davis dances, and afterward her pleasure and gratitude are palpable. The dance classes give her, she says, "a chance to really feel graceful again."

PD patients have long recognized the power of music to liberate them, at least temporarily, from the disease's debilitating constraints. Now a growing number of dance studios across the United States, including some of America's most renowned, are offering classes on a regular basis for people with PD. Students and teachers alike report marked improvements not only in physical symptoms but also in dancers' and caregivers' states of mind. And the first controlled studies of dance and PD -- part of an ever-growing body of evidence that supports the therapeutic value of exercise for people with PD—bear out the empirical evidence. Still, it seems an improbable coupling—dance, the realm of exquisite, extraordinary movement, and PD, which results from the dying of brain cells that produce dopamine, a chemical messenger or neurotransmitter, critical to the initiation of movement. As the disease progresses, patients experience varying degrees of tremor, stiffness, slowness of movement, difficulty of speech, and impairment of balance and coordination.

But to David Leventhal, a dancer with the Mark Morris Dance Group (MMDG) who teaches Dance for PD classes in Brooklyn, the pairing is not at all paradoxical. Dancers and people with PD "really have a lot in common," he says. "We share the challenge of bringing superconsciousness to movement. Neither can take a movement for granted."

It was her intuitive recognition of this similarity that led Olie Westheimer, a professionally trained dancer and now the executive director of the Brooklyn Parkinson Group, to approach MMDG in 2001 about starting the first artist-taught dance classes for patients, their families and caregivers. "Dancers train their bodies, but they dance with their minds," Westheimer says. "When dancers are given a complicated series of movements, they use cognitive methods and strategies to get it. Dancers have been doing it for hundreds of years. [And they know that] the purpose of teaching is to help people enjoy moving."

Dance for PD classes have spread, through dancer-to-dancer training, to California, Massachusetts, Tennessee, Chicago, Toronto and the Washington, D.C., area. Financing and organizing generally comes from local nonprofits such as the Parkinson Foundation of the National Capital Area, which supports the Bethesda, Md., classes. MMDG will offer another teacher training workshop in March. Increasingly now, Westheimer works to educate the scientific community about the ability of dance and music to improve mobility and lift spirits. Last November Leventhal led a group of McCauley's PD dancers in a closed-circuit

demonstration for neuroscientists at their annual convention in Washington.

Neurologist Kathleen Shannon, M.D., a PD specialist at Rush University Medical Center in Chicago who strongly supports the benefits of dance, is designing a randomized, controlled study to compare changes in two groups of PD patients. One group takes regular dance classes with artists from Chicago's Hubbard Street Dance Group, and the other practices another form of exercise such as Pilates.

The first controlled study to examine the effects of dance classes on people with PD, published in December 2007 in the *Journal of Neurologic Physical Therapy*, focused on the Argentine tango, a dance form that researchers at Washington University School of Medicine in St. Louis say targets problems specific to PD patients, such as balance, multitasking, moving backward, initiating movement and moving at a variety of speeds. In the results, ***patients who took part in regular tango dance classes showed significant improvements in balance and mobility when compared with patients who did conventional exercise.***

A peripheral result of the study that was revealed after it had ended was also important. Half of the participants in the tango lessons continued to attend classes, while all those engaged in conventional exercise classes dropped out. The key to maintaining healthy movement "is to remain as active as possible. If they enjoy it, find it engaging, they're motivated to do it." Dance has also proven beneficial in addressing the non-motor aspects of PD, such as depression. Mahlon R. DeLong, M.D., a neurologist and PD expert at Emory University School of Medicine, points out that an alternative therapy like dance, which gets patients "engaged, moving, socializing, feeling their bodies, and gets them out," has tremendous value.

To observe one of McCauley's Dance for PD classes in Bethesda is to sense why this must be so. As students arrive, one parks her cane on the *barre* on the wall. The most debilitated is a thin, gray-haired man who wants to be identified as Ed. He hunches in his wheelchair, his arms and legs rising and falling spasmodically, as a helper rolls him into place in the circle, then sits down in the chair beside him.

Class progresses, like all dance classes, from small, supported movements—think of a ballet dancer at the *barre*—to larger, unsupported movements across the floor. McCauley and her assistant, company dancer Alison Crosby, use the language of ballet as students stretch out their legs in *tendu* and *rond de jambe*, first seated in their chairs, then standing by the *barre*, which Ed uses to pull himself out of his wheelchair, McCauley hovering nearby to help with balance.

Teachers enjoin students to "pull up" their posture to improve freedom of movement, deploy imagery to engage their imaginations and improvise movements of their own. In one favorite opening exercise, each PD dancer and care-partner says his or her name and demonstrates a gesture to go with it. On this January afternoon not long before Inauguration Day, Ed chooses to be the new president-elect. "Obama!" he shouts exuberantly and throws his arms in the air in a classic victory pose.

By the second part of class, when the piano breaks into a familiar tango and McCauley directs the dancers to walk in rhythm across the floor, faces are animated, smiles are spreading, cheeks are flushed and all but Ed swing their arms as they strut. Ed is deeply, and remarkably successfully, engaged otherwise. He is making his wheelchair dance!

My Take on the CPWG Dance & PD Project - *by Marlynn Block*

Dancing is like dreaming with your feet. - author unknown

I do not try to dance better than anyone else. I only try to dance better than myself - Mikhail Baryshnikov

CPWG, The CT Parkinson's Working Group mission statement says that it will "...provide education and support to those affected by Parkinson's disease and ...collaborate with the medical community to enhance treatment and research of PD."

The "W" in CPWG stands for the work that its members do in order to present education and support in quite unique venues and forums. The work of the current year is a cutting-edge dance program that is the first of its kind in the state.

Based on a program developed and presented at their Brooklyn, NY headquarters by the internationally celebrated choreographer and dancer Mark Morris and his dance group (MMDG), the CPWG dance program got off to a rousing start late in 2008. Dedicated instructor and physical therapist Katie Tranzillo facilitated the first few exploratory sessions in a Middletown studio managed by Middletown Health services that carries the intimidating name, "Vinnie's Jump 'n Jive". More than a few regular CPWG members, People with Parkinson's (PwPs) and their care partners hesitated to show up at a place sporting a name that produced visions of trips, falls, humiliation and many opportunities to remain frozen in place as fear created a group of permanent "wall flowers".

Instead, miraculously, using the pace and techniques, the rhythm and slowly building confidence inspired by Katie's own experiences and those she had had working with the MMDG during her visits, the Connecticut group swayed, marched, glided and enjoyed several hours of dance, during which many physical symptoms reportedly "disappeared" for part or much of the class, depending on individual experience.

On the other side of the planet, Israeli therapist and martial arts expert Alex Kerten has developed a unique dance treatment for patients suffering from Parkinson's. The Gyro-Kinetics therapy, which is attracting the interest of patients from all over the world, combines music, rhythm and movement to help patients learn to live with the disease, and gain some kind of control over it. A pilot study suggests that the treatment slows down the progress of the disease, enabling patients to avoid increasing the dosage of drugs.

Meanwhile, in the tiny state of Connecticut, classes are being offered by CPWG both in Middletown and in a new program on the Campus of Connecticut College in New London, beginning June 10 and facilitated by Rachel Balaban, a Rhode Island dance instructor who believes enough in the program to shlep in weekly from a state away!

All classes in the 12 week programs are offered free of charge to PwPs and their partners and CPWG hope to be able to continue funding the programs later in the year and to expand to other areas of the state.

It is a profound experience to be in the presence of a group of PwPs suffering from a wide level of mobility impairments. It is truly awe-inspiring to witness that same group morph into a swaying, gliding, dancing group, on their feet, in their chairs, transformed by the rhythm and movement and forgetting about symptoms and medication timing...if only for those few dreamy moments.

Connecticut Parkinson Working Group (CPWG) presents

Dance & PD at Connecticut College

There is a strange revolution quietly taking place in the Parkinson community: dance. It would seem two things could not be further apart than PD and interpretive dance. However, the Mark Morris Dance Group (MMDG), a world renowned dance troupe, has shown that the opposite is true - people with PD greatly benefit by pursuing dance and have a wonderful time to boot.

Their classes in Brooklyn, NY, their head offices, is jam-packed every week. They

have been featured on National Public Broadcasting; a video of what is going on was presented on Boston TV, and it is catching. We know of groups in Illinois and Massachusetts that have started and the word is that this is just the beginning.

The CPWG is making a priority of bringing a similar activity to Connecticut! Our courses are in the same spirit but tailored to the needs of our folks. We have sponsored a class in Middletown, which has been meeting since March 2009 and another for the residents of Southeastern Connecticut, which starts June 10. We hope that this enjoyable and beneficial activity can be made available to the entire PD community in the state - it is quality time for everyone.

We are pleased and grateful to the College and Dance Department for their wonderful attitude and graciousness in letting us use the superb facilities they have made available. We knew they were smart - we must add enlightened.



Rachel Balaban - come to Connecticut College and find out what is making her smile

Dancing with Parkinson's

Come join us in this joyful dance program designed specifically for people with Parkinson's disease (PD) This special program is sponsored by the Connecticut Parkinson's Working Group (CPWG), a non-profit organization dedicated to educating and supporting those with PD. It is free for anyone with PD, and their caregiver or partner.

Exciting music and clear examples invite you to explore new movements and concepts, to move with the music, and to feel comfort and ease in your movement. The music is carefully chosen to help us embody each type of movement. The movements are selected and modified specifically for people with Parkinson's, and can be adapted according to an individual's ability (including those who are sitting down!). Movements will be delicious, exciting, rhythmic, fluid, grounding, centering, purposeful, or full of breath, and they will become uniquely your own. No previous dance experience is needed! - Release body tension and increase flexibility.

- Strengthen your body's core;
- Breathe more deeply and vocalize more fully;
- Experience different types of music that affect you in different ways;
- Connect with others joyfully and creatively;
- Feel supported as you explore in a safe and comfortable environment;
- Feel power and grace in your movement and in your body;
- Gain new possibilities in movement;
- Increase awareness in your body and how it moves in different ways;
- Experience your aliveness through movement and dance.

FOR THE MIDDLETOWN COURSE

Pre-registration is not required; drop in at any time. A family member or caregiver is encouraged to join us too. Just bring your “two left feet” and a willingness to try something new.

Contacts: CPWG Jackie Dorwin: jdorwin@aol.com 203-453-2655 CPWG email: Cpwg2000 @ gmail.com

Website: <http://cpwg2000.org>

Dance Instructor: Katie Tranzillo: 203-915-9371 katiet@joyfuldancing.com www.joyfuldancing.com

Location: Vinnie’s Jump and Jive 424 Main Street Middletown, CT 06457 860-347-6971, ext 3777

www.vinniesjumpandjive.com Drop Ins Always Welcomed

Dates: Wednesdays, 1:30-2:45

Watch this space for news of continuation past June 23.

FOR THE NEW LONDON COURSE

The classes are not ballroom dancing, but individual, often interpretive or improvised dance. You do not need a partner; however, please invite a partner if you can. There will be a time for an instructor led warm-up as well. The dance class will meet every week on

Wednesdays, 10:30-11:45, Myers Studio (air-conditioned) 3rd floor student center. The first day will be June 10.

There is parking in front of the center and an elevator to the third floor where the class meets,

There is no charge for people with PD and their partners. All levels are welcome - chairs are provided for all, For persons completely mobile to those in wheel chairs.

The instructor is Rachel Balaban, a professional dance teacher.

The music will be from several genres, from jazz to classical to Broadway to ethnic.

Come join us for dance, community and fun.

Need more information? Call 860.572.9965.

Directions: Enter Connecticut College at the main entrance on route 32. At the guard house at the top turn right, then left a few hundred feet on, then immediate right. Just past the library on the left is the student center. Park, take the elevator on the first floor to the third floor. The Myers studio is on your left



Katie Tranzillo - doing her thing

Some comments from the editor: Putting out this issue has been both a pleasure and a chore. The chore part is as usual - getting the right articles, getting them on time, getting them edited, with the right level for our readership, and so on. That was expected.

I did not expect the wonderful cooperation I got from everyone I asked. I set unreasonable deadlines, and they were met; I requested the reading of long articles for background, and they were read; I did not ask for passion, and was overwhelmed that it was there anyway

I want to thank Jeff Lincoln, Deb Weinstein, Marlynn Block, Katie Tranzillo, and Rachel Balaban for their contributions and their spirit - they wrote this Special Edition and it reflects their different personalities and ways of communicating. I should add Jackie Dorwin, a proof-reader *extraordinaire*. I consider myself fortunate in knowing them.

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