

PD SENTINEL

CONNECTICUT PARKINSON'S WORKING GROUP

Fall 2014

In this Issue

Yes! They've Done it Again!
page 1

Editorial
page 2

Brain Games
page 3

Music Skeptic
page 4

FYi
page 5

Bits and Pieces
page 6

From the President
page 7

Calendar
page 8



YES! They've Done it Again!

Little did I know early last year, when I followed up on an e-mail to CPWG from Kathy Smith, that it would lead to a healthy contribution of \$5,000 to keep our Middletown Dance Program going strong. Remarkably this was not just a single contribution last year but an invite back this summer for a repeat and an invite for summer 2015 for yet more. As many of you know this all stems from the Zwick Pro Am golfing event held at the Farms Country Club in Wallingford each summer to raise money to help find a cure and more recently to help a local group such as ours and the dance program.

Lenny Zwick, husband and father, and avid golfer, lost his battle with Parkin-

son's about eight years ago. The event in his honor was started with the blessing of his family. Pros are invited and it's snowballing into a wonderful charitable event that incorporates golf with raising money to combat Parkinsons.

Then sometime last year CPWG was graciously invited by Kathy to join and benefit being a local group in Middletown and I immediately thoughts of our terrific dance program which was beginning to fall on hard times due to lack of funding. While the Senior Center generously gives us a room to use every Monday, we still need to pay the teacher for her time and travel and wisdom and training.

Continued on page 7

Editorial

Kendra Hough, Editor

HERE I AM AGAIN

I was profoundly impressed by our speaker in June, Tracy-Godwin Randolph, certified Therapeutic PD Exercise Instructor (among other monikers). She not only had new (to us) and very interesting information to share with us but she demonstrated a connectedness to the P.D. Community that I feel was genuine and felt by all. She not only encouraged but was able to gain willing participation and evoke many questions about her unique approach. Tracy not only understands how it is, she tells it like it is ...without prejudices of special interest backing. Her approach to why she advises for and against anything is evidence based and she can easily cite her reference materials in support of her choices.

There is no question as to her degree of commitment to teaching and caring for those in the Parkinson's community. Evidently she likes us, and it showed. We need her in the midstate region ... now!!!!

Tracy spoke about the importance of cadence, beat and entrainment. Entrainment is a state of synchrony which can be invoked by music and is the basis of life's rhythms ... It was discovered by a Dutch scientist lining up pendulum clocks and finding that they would eventually swing in harmony together ... entrainment is when women work or live together and all reach their monthly cycles at the same time. Entrainment is when fish swim in schools and all turn at once. Entrainment is when a circle of drummers feel "in the zone", or altogether in a mysterious and wonderful way. The basic scientific law is that two vibrating bodies will eventually reach synchrony in motion. One loses a little energy in the



process and one gains a little. The objects reach balance. It is why crickets in the night seem to chirp as one. All plants and animals experience this.

Since cadence, beat and entrainment also pertain to music we will explore some of the ways music can be used and its importance in the care and feeding of a PWP (you and me). From drumming, to chair dancing, to ballet, to marching... evidence based of course!

FLAILING?

What in the heck is that? A feudal term for jousting? Do I need a horse? Armor? A long pointy, poky thing to stab opponents as I trot by? Nope, just need P.D. And that we've got plenty of! At first intrigued, and then horrified to find myself with one leg outside the covers and foot resting on the floor when I awoke, I determined to keep an eye on that situation. Hmm, it did not seem to matter how far from the edge of the bed I slept ... After months of noticing this ... a change ... instead of one foot hanging out of the bed there were two ... and both of them were mine. Wait a minute ... PWP's hallucinate, myself no exception. Maybe I hallucinated that I was on my back in bed ... with both legs hanging over the bedside and feet on the floor ... not a graceful visual!!

As anticipated a product of P.D. vs product of P.D. meds ... listed often with neuropsychiatric disorders, it seems to be best described as a dyskinesia. It also has a relationship with REM sleep.

...Owlet

the wings of siberian iris flutter in the wind ...

spring peepers scream their availability ...

the tulip tree reaches skyward and spits it's flowers of orange and yellow...

the veery practices melodic scales in the woods ...

thunder rumbles in the periphery ...

meanwhile the fledgling owl clings silently in the rhododendron....

obediently awaiting his mother's return.

Brain Games

By Judith Iovanna



Use it or lose it !” How many times have you heard this phrase in reference to the brain? This is an important alert. The brain, like muscles, it needs exercise to stay healthy.

The brain is a complex organ formed of nerve cells. The nerve cells are known as neurons. These cells are connected to each other by means of synapses. The neurons transfer information between them through synapses. The brain just like the organs of our body, undergoes an aging process. Brain exercises prove to be of great help to stem this aging process

I recently had the opportunity to take a course in brain fitness. It was being given at the Senior Center in my area. It proved to be a tremendous class.

One of the complications of Parkinson’s disease is dementia. Although statistics tell us only 30% of people with PD will experience dementia! If there is a way of stopping this then let’s try doing it.

The brain has six domains

1. reaction
2. visual /spatial
3. Attention/concentration
4. Memory
5. Language
6. problem solving

Playing games that work on each of these domains, is said to improve the function of that area of the brain. This program was aimed toward a healthy brain.

How do we accomplish this task of nourishing the brain ? By playing GAMES!! It is that simple. Now does that sound like fun? There are so many ways to engage the brain in activities that will enhance the ability of the brain to form new cells and help to support good brain health.

Here are some very interesting and fun challenges for your brain:

If you watch TV, try tuning into Jeopardy or Wheel of Fortune. Play along with the contestants.



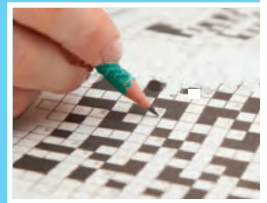
When someone is making a speech, try counting the number of times the speaker will say “um or you know”.

Do you play Suduko, crossword puzzles, word jumbles or other word games?



Make the effort to include these in your daily activities.

These are excellent ways to enhance brain functions. Get out of the house and be active. If you can, join a walking group, take swimming lessons (most venues will provide assistance when you explain that you have PD). Diet is important. There are so many foods and/or supplements that will positively affect the brain. Research this on your computer.



Let’s not forget the important of music. Did you always want to play piano or drums. Well it is never too late. Visit your local music store and ask about lessons. There is no age limit.

At the nearby senior center I am part of the “Young At Heart Ensemble.” We sing and play music. It is fun and enjoyable and also so important for the brain. The brain is positively affected by music. So many things in life can be remembered through a tune. Can you recall this little tune from grade school? “In 14 hundred and ninety two, Columbus sailed the ocean blue”...

So have fun and exercise that brain and don’t forget Use it so you won’t lose it!!

Music Skeptic

By Kendra Hough



Ok.Ok. I will admit it. When all the buzz started about P.D and music I ignored it. I was in a drumming circle, not “playing” like my companions but accepted despite that and joyous to be part of the group and experiencing the richness and variety of the djembe.

I know a guy that has 43,295 musical pieces on his ipod ... silence anyone? For him it interrupts the mechanism of FOG syndrome, freezing on gait.

A lady friend plays bluegrass constantly, follows bands around New England and again uses music to combat effects of neurodegenerative disease...even heading off into a bluegrass cruise.

Everyone loves their own kind of music...some love it all and constantly surround themselves with song.

Am I the odd man out? I do not listen to much music ... and my attachment comes in waves ... like waves of Crystal Gayle, or Pete Seeger, Beatles, Garth Brooks ... People in Low Places. Sometimes I think it is my inability to focus on more than one thing at a time and that I cannot accommodate to the distraction of background music ... like walking and chewing gum ... or like having nuts in the ice cream ... an interruption. I am sure I must be in the minority.

Despite whatever long hidden and unremembered reasons I am not “into it” as they say. Rhythm however was enough to addict me. And my preferences might relegate me to “low places.”

Nonetheless, rhythm is the backbone of music and just as executive dysfunction may limit my recall of sequences to items one and two ... it may also diminish my appreciation of song ... my loss ... wait a minute ... i said song ... but I do appreciate sound however ... Scottish bagpipes in the shadowed corners of Edinburgh Castle, the merry and not so merry trad songs in an Irish pub, the tempo and beat of fife and drum, the beauty of a gong bath, long remembered sound of carillon from decades past and its accompanying heartache, and the addictive beat of dun dun and djembe, that reunites me with souls throughout time. I can no longer deny being touched by music ... engendered by the power within.

Three things opened my eyes to the broad implications for music and P.D. The first was swallowing difficulty and the training involved in improving that. It sometimes includes a scale of very loud “ah's”. Hmmm that's a musical word ... scale ... set forth by one's mouth!

Secondly, a group member sent me an article from BBC news on the use of ballet with PD. How intriguing I thought. In addition, Michelle Hespeliers demo on exercise, boxing and dance brought me to the taste of ballet. I loved the graceful feeling ... hmmm maybe there is something to this stuff.

In an article entitled “En pointe to tackle Parkinson's disease (3/13/13 by Loma Stewart,Health Check, BBC World Service), ballet has been shown to influence balance, coordination, and increases artistic expression. In the classes, run by the National Ballet, participants express delight with the exercise, beauty of the music and social opportunity. A study at Univ. of Roehampton, is measuring the changes over time.

Some, like Linda Ronstadt, say you cannot sing with P.D. Perhaps not to her high expectations, but the evidence is to the contrary. Despite affect of P.D. On mouth, throat, vocal cords PWP's can be trained in better use of diaphragm to enhance speech and singing voice. Projection is emphasized as well as focus on articulation.

In “The Healing Power of the Drum” Robert Lawrence Friedman, a psychotherapist ventures to say that it is the beat that produces a physiological change enhancing healing. Healing is not the same thing as curing.Healing is a state of acceptance and peace despite the presence of disease. Curing is the removal of the disease ... often wished for and so often unattainable.

Music has healing power. It, as well as entrainment, acts on the brain and is causative. That means something happens. It might be a feeling of well being, it might be a change in attitude or mood. It might enhance feelings of belonging, or acceptance, or your acceptance of your changing body

MY PARKINSON'S JOURNEY

Bits & Pieces

By Jill R. J. Baldwin



Parkinson's disease is a thief. Like a cat burglar dressed head to toe in black, prowling through night's darkness and nimbly appearing out of nowhere, it pockets your most valuable possessions. Then the stealth intruder has the audacity to repeat the infiltration and return for more, taking one precious jewel at a time.

These intermittent raids on my brain and body by Parkinson's disease make me feel as if I'm losing bits and pieces of myself. The way I talk, walk, sit, stand, blink and think are being burglarized. I now constantly scan the horizon to detect if the intruder is skulking nearby, waiting for the opportunity to pounce again. Although the perpetrator has eluded capture, most of my stolen property is eventually recovered. However, the pieces have been cleverly altered, so at first glance I don't recognize them.



I have two young granddaughters, each of whom possesses their own unique personality and talent. Abbie, the first born loves to dance. As soon as she could stand and walk we would dance together, interpreting whatever music was playing in our own avant-garde style. And now, whenever the girls come to Connecticut for a visit, Abbie accompanies me to my Dancing for Joy class. Dancing helps me retain some of the bits and pieces the thief is attempting to acquire. Dancing is my antidote to the poisonous effects of Parkinson's; it trains me to think, coaxes me to walk with grace, assists me to stand upright, and helps me to sit and rise from a

chair elegantly. I believe that Abbie understands why her Grandma dances. I can see it in her smiling face when we wink at each other after our performances. I call her my "Dancing Queen."

Amelia, my younger granddaughter, always declines the invitation to attend dance class. Obviously "Dancing with Grandma" isn't her thing! And that is fine. Amelia and I put puzzles together. Actually, she makes most of the interlocking connections. This young child has an amazing ability to organize objects in her mind, sorting puzzle pieces by corner edges, straight lines, colors, and partial pictures. She approaches each new puzzle as a challenge to conquer, assessing how the group of edges and contours will mesh together. She methodically plots her strategy and like magic, the puzzle comes together. I call her my "Puzzle Queen."

Parkinson's sometimes makes me feel like I'm a living puzzle. The misshapen pieces of me lie scattered on a card table in my family room for weeks, patiently waiting for me to recognize and join them together. The good news is that although some of my puzzle pieces have been modified, I am learning how to assimilate each one into my renovated life. Abbie has taught me that there is more than one way to dance through life. Amelia has helped me realize that the challenge of putting one's life back together can be innovative and rewarding.

The Parkinson's thief may not be apprehended immediately but the authorities are closing in on him and I am vigilantly keeping him at bay. In my revenge against this criminal, like a Clint Eastwood character, good will always prevail over the bad and the ugly. Bits and pieces lost can be found and transformed to create a new life with colorful meaning. When life presents me with a puzzle, I'm going to pick up the pieces and...make my day!

FROM THE PRESIDENT

Progress Report

By Jeffrey LaGrange



A lot seems to be happening at CPWG lately so I thought I'd sit down and write our members to keep them informed.

First and probably most important, the board met several times to decide to cut the list of people who were receiving our quarterly newsletter. We put a notice in one newsletter telling people that this would be their last copy unless they contacted us to tell us to continue. It was a major success. We went to over 400 newsletters being printed (and imagine the postage on that) to about 100 and imagine the postage we're saving. And even with 100 being printed we still have many left over for our library and to give out when needed.

Our Dancing with Joy/Dancing with Parkinson's programs are all doing very well. As you saw on the front cover, we received a generous donation of \$5,000 for the Middletown Dance program, and I'm told the New Haven one is doing well too.

So far, so good. The newsletter is widely distributed and is getting glowing reviews. Thank you to everyone on the newsletter team, Kendra, Jill, Judy, Lisa and Jean.

Our Treasurer, Buzz Baldwin has been busy cutting expenses and showing great numbers on the financial reports that he keeps me informed on.

We do ask that people at least try the dance programs and if you need more information, check in with our vice-president, Judy at the sign-in desk at the next meeting. We have flyers for almost everything.

Jill Baldwin, not only deals with most public relations and books most, if not all, of our speakers but she is very involved in trials with the Michael J. Fox Foundation. Speak to Jill and she'll hook you up.

We're here to help, inform, education, motivate and everything else. Let us know what we're doing wrong and also let us know what we're doing right. We encourage your input. CPWG is working for YOU. We need to know if we're on the right track or if some changes are needed.

And finally, thank you to everyone for coming to the meetings and being involved. I know it's not always easy – it's not always easy for me either. But I firmly believe we must keep on keeping on! Show Parkinson's who's the boss.

YES! They're Done it Again! *Continued from page 1.*

So here I am again, accepting a rather "large" check for \$5,000 that will keep the Middletown Dance program going full steam for a year. Our thanks go out to Kathy Smith for that initial reach out to us and of course to the Zwick family and all the golfers and non-golfers who play such an important role in raising the money making sure everyone has a great time as well.

I invite you all if you already have not attended the

dance program to join us on Mondays at 1:30 pm at the Senior Center in Middletown. As they say in the musical "Cabaret" – what good is sitting alone in your room – come hear the music play. Great music, laughs mixed with hard work at times and above all, great people to share some time with. See you Monday and I'll save a dance for you. Lenny would be happy



52 Princeton Drive
Middletown, CT
06457

Calendar

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

CPWG Activities:

Regular 3rd-Saturday-of-the-Month Meetings,
*10:00 a.m.-Noon. Middlesex Hospital, Middletown, CT. Visit us at www.facebook.com/CPWG.org
www.cpwg.org*

October 18 – Speaker will be Laura Richling, one of the trained instructors in dancing with Parkinson's has agreed to bring a class to our meeting.

CHANGE: Note the November Meeting Will be on the 4th-Saturday-of-the-Month.

November 22 – Andy Degling, LPC, NCC Life Changes, will talk about mindfulness and relaxation

December 20 – No meeting this month. Happy Holidays! See you in January.

Events:

Nursing Grand Rounds
*Thursday, October 30, 4:00-5:30 PM
Middlesex Hospital North 1 conference room
PD panel discussion with Kendra Hough (CPWG) and Steve DeWitte (CAP)*

Dancing for Joy Open House
*Wednesday, October 8, 10:30-11:45a.m. New London
Monday, November 11, 1:30-2:45 p.m. New Haven*

BeatPD Today
*Fall exercise classes start. For more information
www.beatpdtoday.com*

Dance for PD locations
www.danceforparkinsons.org/locations

MADPA
*For alliance support group meetings and activities
www.allianceparkinsons.com*