

Connecticut Parkinson's Working Group

Newsletter

February 2004

Support for this newsletter comes from **Pfizer Corporation** and the donors to **CPWG**.

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The Hospital Walk

Gunilla Norris

It's nine o'clock in the morning. We have managed to get into the Middlesex Hospital and climb the stairs to the second floor. The doors to our conference rooms are locked (again!) despite the advance arrangements and the reminder call to Buildings and Grounds.

At 9:15 we are six, here to practice meditation. What to do? We decide to practice walking meditation in the hall – a time honored form done in most zendos. In my mind I give our little practice a name, “the hospital walk”. Everyone seems willing to try. (Is it the PD personality to be good-natured? If that is true I bless the fact and am grateful. We are, after all, just beginning. This is only the second time we have met and the conditions are challenging).

“Observe, with as much interest and patience as you can apply, the raising of your foot, the placing of it, the shifting of your weight, the raising of the opposite foot.” These are the instructions. The object is not to get anywhere. The object is to be completely present to our experience of walking. Lou, one of the six, comments that with PD he has to pay attention to his walking in any case. Disturbance in the gait. Well, what's it really like? How do we really walk now? Have we paid that kind of exquisite attention?

We come to the end of the hall. For some PD patients, turning around is excruciating. What if we didn't resist that difficulty? What if we could, for a little time, forego impatience, frustration, and fear of the future when things might be worse? What if we could simply observe how we actually manage to turn the corner and walk back down the corridor? The groups does just that, watching every step, aware that it has taken millions of years for a human being to walk upright. Life was not in a hurry to grant us this capacity! Now we can walk with gratitude for all those prior ancestors who made it possible for us to walk this corridor. We can also decide to dedicate our walking to others who cannot walk now – our friends in wheelchairs and in beds. Aware of them we cover another kind of ground.

So then the man from Buildings and Grounds comes at last. Our room is available and we can sit down. What do we notice about ourselves? Everyone is a bit calmer and certainly more present. We have only practiced for fifteen minutes. Not a long time to have gained that small measure of equanimity.

We can continue to practice walking meditation at home. Many times a day from the bed to the bathroom, from the sofa to the kitchen, aware of every step we can grow more centered and peaceful. It is just as easy to walk mindfully appreciating the motion and whatever ability we have as to walk with frustration and preoccupation. Perhaps at the next CPWG meeting we will do “the hospital walk” again. Locked doors won't stop us. It's nice to know we can practice just about anywhere.

The following is one in a series of occasional interviews conducted by Jeff Lincoln. We thank Peter and Nancy for agreeing to be interviewed – it is not always easy

opening up a public place. Perhaps you think someone you know would be a good subject for Jeff – please contact him, or me, if you do. Stan

An Interview With Peter & Nancy O. in August 2003

Jeff – Just a few questions to start. When were you diagnosed and how old are you?

Peter – I was diagnosed in October of 1992. 11 years ago. And I'm 45 now.

J – How did you find out you had PD?

P – It started off as just a little twitch in my index finger. That went on for about a year or two before I noticed it. But my sisters noted it and told me I should have it checked out.

Nancy – I noticed it on our first date.

J – So you, Nancy, diagnosed it as PD, or was it just something wrong?

N- I figured it was PD, I couldn't think of what else it could be. That was May 17th, 1992.

J- How do you remember the date so precisely.

N – Because that was our first date!

J – Did you encourage him to go to a Doctor?

N- Not right then, but a couple of months later when we were getting more serious. Maybe 3 or 4 months after we met.

P – Then I went to my General Practitioner. He told me I had PD.

J – So you were diagnosed by your regular Doctor?

P – Yes, but he recommended me to see a Neurologist, Dr. H. His attitude was “You have PD. Here's some Sinemet.” He put me right on Sinemet.

J – You would be amazed how many people that I talk to who tell me something similar, no explanation of the symptoms, no explanation of what to expect, no comforting, just “Here's a pill. Come back in X months”.

N- We got a couple of names at Uconn, but they weren't PD specialists.

J – Did you go and find another doctor after that?

P – Yes, then I went to see Dr. R and he told me “Don't go to a support group. It's just a bunch of old people who will depress you.” I didn't like the way he said that. It really turned me off, but in reality it was true. It did depress me to see all these people with severe symptoms. I stopped going. About 3 years later, I started going again. At that time I knew what was going on and could get something out of the meetings. I knew what stage I was at.

J – You swung between “I'm so much better than these folks” and “I'm going to be like these folks.”

P – Exactly!

N – By that time he had gone down to Ken Marek who had him cut back on the Sinemet. His approach was to ease into the medication. You don't need both barrels right away.

P – On Sinemet alone, I was so nauseous that I sometimes put my head down on my desk and sleep for hours. My boss didn't know what was going on.

J – What were you doing at the time?

P – I was a Manufacturing Engineer. But at that time I was in Strategic Planning.

J – We'll come back to your work later. Fast forward to now. What medications are you on?

P – Just about everything! (laughs): Sinemet, Comtan, Permax many times per day. In the past Eldepryl and others.

J – Looking at your kitchen counter, I see that you have a lot more pillboxes than I do.

N – As your dosage gets increased, you need more pillboxes. It's like starting with a VW and buying up to a mini-van as you have more children.

J – I take the 7 compartment containers and cut them up to make other sizes.

N – We'll have to try that.

P – They don't make 8 compartment so I use 2 four compartments.

N - When we travel now, we carry a special lunch box filled with medicines. We also have a backup set, just in case.

P - Then I carry a backup in case I lose Nancy.

J - I carry a pill vial with some of all my meds; I can build several doses if need be.

J - Let's return to work. How did your boss take it when he learned of your PD?

N - He had a very good boss.

P - I had good people all around me. They opened up to me. They asked a lot of questions. Even my family isn't as open to me.

N - Peter has a lot of brothers and sisters, and some of them get it - some don't. But none of them are around all of the time.

J - How long did you work after you were diagnosed?

P - Until 1999. 7 or 8 years. I noticed after a while that I was holding the group back. Finally it got to a point where I said "That's it, I have to stop working."

N - I think it was a mutual thing between you and your boss. You had a very stressful job, and you are a very conscientious person. The more you felt that you weren't keeping up, the worse it got.

P - During the layoffs, we took on more work than we could do. In the end I was working 16-18 hours a day just trying to keep up. Before that I didn't think about retiring.

J - Moving on, how do you feel about changing medicines and trying new things?

N - People want an instant effect. It's frustrating to have to wait. If you fool around with more than one medicine, you're not sure which one is doing what.

J - I think of great interest to PWP is alternative choices and routines. You have recently had a swimming pool put in; how do you use it and what does it give you?

P - We were nervous at first, but it turns out that it does a lot for me physically. My only concern is getting in and out of it when nobody else is nearby. If I lock up, I can't get out by myself.

N - Neither one of goes in without somebody around.

J - What kind of exercising do you do?

P - I use it for physical therapy. I took a class for 3 months. It was a long way from here, but I missed half the classes, because I couldn't drive when I was off. With the pool right here, I have more use for it. I still drive but a lot less.

J - What's a typical exercise in the pool?

P - Leg stretching, twists, head tilts, marching with arms swinging and feet flat on the heels, side stepping. I also walk against the current. Sometimes I take deep breaths.

N - I swim for about one-half an hour. I also do stretching or exercise. It relaxes me.

J - Nancy, you are a lawyer. How does your working long hours impact your home life?

N - Lately I've been working long hours. The fact that Peter's home has allowed me to not worry about my hours. I don't have to worry about letting the dog out. In that way, his retirement has made it easier for me. I was glad when he retired.

J - Are there things you have given up because of PD?

P - Tennis and softball. I have started to increase the amount of yard work I do. Sometimes I overdo it. I never rest.

J - Nancy, did you say that you found long-term care insurance for Peter after he was diagnosed?

N - We looked around but didn't expect that we would find LTC for him. Our financial planner said there might be one or two who would insure Peter if I also went on the plan. He came up with this company called Penn Treaty. They came out and underwrote him. This was 4-5 years from now. I don't know if they would accept him now. So the two of us have this long-term care insurance. It's nice to know it's there. Maybe we were just lucky.

J - How do you find people, especially strangers, treat you?

P – I try to be as independent as possible, but when I turn off, I just ask anybody next to me to get a glass of water or to take out my pills. Most people are very willing to help. People respond with open arms. They want to help.

J – Any words of wisdom before we finish?

P - There are some issues I have to deal with. Being sensible but not afraid. That's really hard to do.

J – Do you have any advice for someone recently diagnosed?

N – It's tough. Newly diagnosed PWP want to know but don't want to know. Look far enough ahead to have a general sense of what you have to do but not so far that you get overwhelmed. It takes practice to do this. We have learned a lot, but I'd never want to go through it again. When you're ready, read a book or more on PD, maybe starting with "Lucky Man" by Michael J. Fox. Do as well as you can. Use your religion or anything else that helps.

J – Thanks for the advice and for spending the time with me.

Levodopa May Be Addictive By Jennifer Warner, WebMD Medical News
Reviewed By Michael Smith, MD on Monday, November 24, 2003

Nov. 24, 2003 -- PWP may become completely dependent upon a drug commonly used to help restore their muscle function and retain their independence. A new report suggests the popular PD drug levodopa may be addictive, especially in people who use the drug and do not actually have PD.

Although more research is needed on the possible addictive properties of levodopa in PWP, researchers say the findings may help explain why PWP frequently crave their next dose of levodopa. "Although the impatience, the emotional dependence, and the craving to receive the next dose of levodopa might resemble addiction, this behavior has been attributed to the urge to overcome the incapacitating motor dysfunction," write researcher Israel Steiner, MD, of Hadassah University Hospital in Jerusalem, Israel, and colleague.

Stopping Levodopa May Lead to Withdrawal

But in a report published in the Nov. 25 issue of the journal *Neurology*, researchers describe five people who displayed signs of addiction after being treated with levodopa for restless leg syndrome or an incorrect diagnosis of PD. According to the report, the patients suffered from psychological and physiological symptoms of addiction and withdrawal from the levodopa when they were weaned off the drug. For example, one woman with restless leg syndrome who took levodopa increased her dosage of the drug by seven times without consulting her doctor and suffered from agitation, palpitations, diarrhea, and sweating when doctors tried to replace levodopa with another drug.

Researchers say that because levodopa works on the same reward center of the brain that has been associated with the addictive properties of other drugs like cocaine, nicotine, and alcohol, it's plausible that addiction to levodopa may develop. They say their observation of the potential addictive properties of levodopa should be examined in larger studies involving people with and without PD.

SOURCE: Steiner, I. *Neurology*; Nov. 25, 2003; vol 61: p 1451.

<http://my.webmd.com/content/Article/77/95420.htm>

PD medication linked to gambling **American Academy of Neurology**

ST. PAUL, MN – Excessive gambling could be an unfortunate yet rare side effect in PD patients who take certain DA agonists, according to a study in the August 12 issue of *Neurology*, the scientific journal of the American Academy of Neurology. Researchers at Muhammad Ali Parkinson Research Center in Phoenix, Ariz., examined the data of 1,884

PD patients who were seen during a one-year period. Nine patients – seven men and two women – were identified with pathological gambling.

"The risk of gambling problems in a PD patient is very small," said study author Mark Stacy, MD, who is now the medical director of the PD and Movement Disorders Center at Duke University Medical Center, Durham, N.C. "However, it may be appropriate for doctors to inform patients of this potential risk, particularly in their patients taking relatively high dosages of a DA agonist, and with a documented history of depression or anxiety disorder."

The nine patients were taking both levodopa (a drug that the brain transforms into DA) and a DA agonist (a drug that activates the DA receptor in the brain). Eight of the patients took pramipexole as their DA agonist, and one patient was on pergolide. None of the other patients taking ropinirole (a different DA agonist) or only levodopa were identified with a gambling problem. Most of the patients were in advanced stages of the disease. On average, they had been diagnosed with PD for more than 11 years before gambling problems began. The patients were taking pramipexole or pergolide anywhere from six to 64 months before the onset of gambling, and seven patients started gambling within one month of an increased dosage of the DA agonist. None of them had a previous history of gambling.

The gambling behavior was severe enough to cause financial problems, and two patients had losses more than \$60,000. After a family member or caregiver noticed substantial financial loss, the patients' treatment regimen was changed. For most patients, the gambling could be controlled or stopped under a new treatment plan. Eight patients had the DA agonist switched to lower comparative dosages of ropinirole, and the remaining patient received a decreased dosage of pramipexole and an increased dosage of levodopa. Some patients also attended Gamblers Anonymous meetings. Caregivers secured patients' credit cards and watched for signs of a gambling relapse.

Two of the patients who switched to ropinirole also required additional psychiatric treatment, and one withdrew from the therapy program and later committed suicide, while dealing with a number of issues unrelated to her PD. The rate of pathological gambling found in the 529 subjects taking pramipexole (1.5 percent) is only slightly higher than the reported rate in the general population (.3 to 1.3 percent), and the availability of casinos in a retirement and vacation setting like Arizona may have contributed to the development of this behavior in the patients, Stacy noted.

"However, this clinical observation suggests that higher dosages of DA agonists may be a catalyst to bringing out this destructive behavior," said Stacy.

DA is a chemical substance produced in the brain that enables people to move smoothly. PD patients have a severe shortage of DA, which results in symptoms including tremor, rigidity and walking problems.

Note: DA = dopamine

The American Academy of Neurology, an association of more than 18,000 neurologists and neuroscience professionals, is dedicated to improving patient care through education and research. A neurologist is a doctor with specialized training in diagnosing, treating and managing disorders of the brain and nervous system such as stroke, Alzheimer's disease, epilepsy, PD, autism and multiple sclerosis.

(Following is part one of a two part article. Those of us who have seen Steve at meetings have seen the almost unbelievable change – here is his story, first person.)

DEEP BRAIN STIMULATION THERAPY FACT SHEET

DBS: FDA APPROVED AND MEDICARE COVERED PATIENT: STEVE HOLAHAN

FACILITY: BETH ISRAEL DEACONESS MEDICAL CENTER, BOSTON, MA
(A HARVARD MEDICAL SCHOOL AFFILIATED HOSPITAL)
DR: DANIEL TARSY, NEUROLOGIST, HEAD OF MOVEMENT DISORDER CTR
LISA SCOLLINS, MSN, APRN DBS EXPERT/COORDINATOR 617-667-9885
DEVICE: MEDTRONIC'S ACTIVA THERAPY USING SOLETRA NEUROSTIMULATOR
OPERATIONS: (2) 1. BILATERAL ELECTRODE IMPLANTATIONS IN SUBTHALAMIC
NUCLEUS (STN)-NO
PD MEDS: NONE, CONSCIOUS THROUGHOUT,
DURATION: 8-10 HRS. 1-2 DAYS HOSP STAY. 2. ONE WEEK LATER STIMULATORS
IMPLANTED IN CHEST AND CONNECTED TO ELECTRODES – DAY SURGERY, PD
MEDS OK, FULL SEDATION, ABOUT 3 HRS -- 30 DAYS AFTER THE FIRST
OPERATION STIMULATORS TURNED ON-NO PD MEDS AT INITIAL SETTINGS. --
FOLLOWUP: MONTHLY FOR 2 MONTHS THEREAFTER 4X/YR.

It's been a year since two tiny sets of electrodes were implanted deep in my brain. It has been 11 months since the two stimulators, connected to the electrodes were turned on. The stimulators are small programmable battery packs, similar to a heart pacemaker. Other than for one post-surgical study lasting about an hour, the two systems (a stimulator connected to a set of electrodes for each side of my body) have remained on 24/7/365! The effect of this wizardry of modern medicine on my PD has been so dramatic that the term miraculous is often used when comparing the before and after. Before going into some of my reactions to the changes brought on by my DBS therapy, I would like to offer my layman and patient's view of how and why this electrical hardware based solution works.

While the precise reasons for PD are still a mystery, we do know that it causes premature and accelerated cell death in a part of the brain that produces a critical chemical, dopamine. This chemical plays a crucial role in the brain's control and initiation of muscle movement, both voluntary and involuntary, literally from head to toe. One result of this dopamine shortage in the PD brain, is that other areas of the brain become hyperactive, leading to many of the worst symptoms of the disease, tremor, rigidity, freeze ups, cramping, and abnormal movement and flailing. Imagine for a moment, a computer controlled robotic arm on a factory assembly line. To accomplish its task and to function smoothly with the rest of the line, the arm depends on a series of very precisely timed electronic pulses from the computer. Introduce some random pulses and that robotic arm will move chaotically! Even if these extra pulses are not random, but very precisely timed or harmonic, a robotic arm told to extend and contract repeatedly at very close intervals will show a mechanical tremor. And if the robotic arm receives the pulse to extend and contract simultaneously, the result would be a hopelessly rigid arm frozen and immobile. When one of the pulses stopped the arm would suddenly and violently snap in the direction commanded by the remaining pulse, there now to be locked rigidly in that new position.

This model of the brain as a massive computer sending millions of controlling electric pulses while conceptually accurate has been of little therapeutic value. The computer model of the brain explains and describes the symptoms, but until now could not explain the treatment of PD. We lacked a keyboard or bank of switches to directly change or control the brain's electronic output. Instead we had to use a great pot of chemical stew into which we threw our assortment of PD medicines. The hope was that enough drugs survived the digestive and blood stream stew pots, without derailing other necessary body functions, to finally reach the brain. The drug survivors that crossed the brain-blood barrier then triggered the necessary chemical reaction. If it was the right place, at the right time, then the right electrical pulse was sent to move the muscle. Rube Goldberg would be proud! No wonder that my PD drugs were so unreliable.

My conception of DBS is that it is the keyboard to directly control my brain's electrical output. My arm has replaced the robotic arm of my analogy, now properly functioning. However, it is important to keep in perspective that while DBS is a direct electrical therapy for my brain, it still is not a cure. But as therapy DBS for me has been a miracle for which I am most thankful. *(In my next article I will focus on how DBS has effected my life.* **Steve Holahan)**

Comments on the January Meeting

Six faithful folk were there at 9:15 to take advantage of Gunilla's meditation session, her second. Once again the doors were locked and not opened until 9:35 even though security had been called several times about getting doors opened by 9 – sigh. Not one to let a little thing like that bother her, Gunilla forged ahead and taught the group about walking meditation – see the article.

We covered several of our current needs before the meat of the meeting and it was a sign of our maturation that there were members, some of whom were new at this meeting, who volunteered for important jobs before being asked. That is a clear sign to me that people realize we are in this together and the more participation the more the benefit to everyone.

We started the open meeting about eleven and right from the start there was animated conversation. Michael O'Brien brought up the issue of metals in the body and galvanic action (no need to know anything about this for these comments) after which followed a superb discussion involving many others who brought their experiences to bear on the question of metals and reaction; we were fortunate to have a metallurgical engineer there – Ron Caron. From this part of the meeting the importance of free discussion was again made abundantly clear. We need to have more time devoted to free discussion.

Comments:

--We should nurture the efforts of Gunilla; what she has to offer is clearly important to several members.

--We should have plenty of discussion time. To accomplish this we could schedule more meetings, say during the months we now do not have meetings. We could just have fewer speakers. We could split every meeting between speaker and discussion. We will discuss these options at the March meeting.

--We should say that if anyone has an idea she/he should bring it up. This has always been the case, but it needs to be said every once in a while.

Stan

Getting the Newsletter Electronically

Jeff Lincoln

At the last CPWG meeting, I volunteered to build up a list of people who would be willing to receive reminder postcards and/or Newsletters by email rather than US Postal Service. If we could get people to accept this new method, we would save significant costs. We intend to start with the Reminder Postcards now and add the newsletters later. If you are willing to receive reminders of our meeting dates and locations by email, send email to me at jeffrey.lincoln@yale.edu. Please put "CPWG" in the Subject: line and "Email reminders to <Your Name>" in the body. We'll do the rest. By the way, it's perfectly acceptable to continue to receive reminders by US Mail if you prefer.

Miscellaneous Comments on the Upcoming March Meeting

If you are concerned about coming to a meeting because you can not get there on time or you fear you may have to leave early, DON'T! Come at any time, leave at any time. WE WANT AS MUCH PARTICIPATION AS POSSIBLE – IT IS GOOD FOR ALL.

There will be a short presentation at the meeting by the manager of a doctor's office; she will give us valuable insight into how each of us can deliver information packets from CPWG to our doctors with the greatest probability of success. Marge Krawczynski will coordinate. This effort can be a great benefit to newly diagnosed PWP. Please do it.

Don't forget the 9:15 meditation group.

We will consider whether we want to meet more frequently than we do now.

There is a good chance that a woman with PD who started a business in handmade commode covers will be there to tell us her story.

We hear that Dorre Singer is holding an art/craft juried show at the Lawrence & Memorial facility in Old Saybrook in early April. Stay tuned.

Preview of Some Articles in the Next Newsletter

University of Calgary neuroscientists have discovered how the brain tells the body to move, research that could give new hope to people with PD. The researchers say they have greater understanding of how the brain processes sensory "cues" that prepare the body for action, which may some day lead to new or different treatment for PD.

"We think that TMS (transcranial magnetic stimulation) makes patients' brains more sensitive to the medication he or she is already taking," says Dr. Lomarev, of National Institutes of Health in Bethesda, Md. This therapy has been tested and used in depressed patients for more than a decade. Doctors say the study with PD patients will likely continue for several years.

A team of researchers, led by physicians at the UC Davis M.I.N.D Institute, have discovered a new, progressive neurodegenerative disorder that predominantly affects men over age 50 and results in tremors, balance problems and dementia that become increasingly more severe with age. A significant but currently unknown number of adults with these tremor and balance problems are being diagnosed as normal aging, PD, senile dementia and Alzheimer's disease when their condition may be accurately and easily identified with a standard DNA blood test ordered by their doctor.

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**DISCLAIMER: Articles in this newsletter are for information only.
Any questions of treatment should be discussed with your physician.**

WRITE! your representatives in congress.

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