

Connecticut Parkinson's Working Group Newsletter

January 2002

CONNECTICUT PARKINSON WORKING GROUP MEETING

19 Jan 2002

at the Connecticut Valley Hospital, Middletown from 1 PM onward

Saturday

Refreshments (drinks & snacks) provided by Brian C.'s employer Crystal Rock.

Directions to Connecticut Valley Hospital, Haviland Hall, Middletown, CT

From Route 9 Southbound:

Exit 12 - Silver Street exit, then left onto Silver Street. Take first right onto Eastern Drive. Go left at main entrance onto Flood Dr. (greenhouse on right hand side). Follow Flood Dr. to first stop sign; at stop sign (in front of daycare center), take a right onto Harvey Drive. Entrance to parking area is right after daycare center on left. Haviland Hall is directly across from parking area and just before the A frame chapel.

From Route 9 Northbound:

Exit 12 - Bow Lane. Right at the exit onto Bow Lane, an immediate left onto Harvey Drive. Parking area is on your right in front of A frame chapel. Haviland Hall is directly across from parking area.

Car Pooling: If you need or can supply a ride PLEASE contact Jackie Dorwin.

If there are any questions you may email Jackie Dorwin at jdorwinataol.com, telephone 203.453.2655, or Stan Wertheimer at stan.wertheimeratgmail.com, telephone 860.572.9965.

Editorial

Stan Wertheimer

You may not notice it, but this newsletter is different from all previous issues: Many of the contributions "appeared" without my having to ask for them, and there is a significant male presence. In the spirit of Jon Barlow, I had a Crazy Idea that there should be articles by men as well as women, and people should feel comfortable writing for the newsletter; it has come about in this edition, and I hope it continues.

A theme is the PD personality, with Jon's article and that by last meeting's speaker Dr. Toni de Marcaida. We continue to be fortunate in having an interview, this time both participants being PWP (Roger B. and Jeff Lincoln) – let's keep that up too! Steve Holahan has addressed an important issue on which there will be more in the future.

The upcoming meeting will be one that we all look forward to where there is no speaker and we get a chance to share our thoughts, fears, joys, and concerns with each other for a longer time. There will also be an update on the educational initiative in which Jackie and I are involved, with a call for help from others.

We will be trying out a new idea in April, which was suggested by Tom Sullivan: Workshops preceding the meeting, from 10-12. The topic for the first set of mini-workshops (30 minutes each) is fitness – stretching, yoga, tai chi, walking, swimming, and so on. Please think about what you would like in the general arena of fitness and let's all talk about it at the January meeting; also think about different ways we can structure the workshops and themes for others we might have.

Minutes: Connecticut PD Working Group Meeting – October 13, 2001

Stan Wertheimer opened the meeting at 1:15 P.M. at Haviland Hall, Connecticut Valley Hospital, Middletown, CT. He introduced Dr. Toni de Marcaida who recently joined the Hartford Hospital and the University of Connecticut Medical Center to start a Movement Disorders Center for Parkinson's Disease and other neurodegenerative diseases. Dr. Marcaida gave a very interesting presentation titled *PD Knowledge and Empowerment Through Research*. She started with an historical perspective on developments in PD research and treatment then went on to discuss milestone research studies and the design of clinical trials.

Stan mentioned that Jackie Dorwin is a member of the Board of Directors of the Institute for Neurodegenerative Disorders (IND) which was founded by Dr. Marek and Dr. Jennings. The Connecticut PD Working Group has initiated a collaboration with IND on an educational initiative directed toward newly diagnosed persons with Parkinson's. Funding for this project to educate those who are not familiar with PD will be requested from pharmaceutical companies. Members of the CPWG are encouraged to become involved in the development and implementation of this exciting program. A successful communication effort throughout Connecticut could serve as a model for other states to follow.

Members were encouraged to provide articles for the newsletter. The following topics were suggested for future issues: PD & hospitalization, difficulties in diagnosing PD, initial reactions after PD diagnosis, how to define PD, book reviews, and interviews with persons with PD or caregivers. Jackie Dorwin reminded the group that annual subscriptions to the newsletter for friends and relatives are available for a \$3.00 contribution.

Brian C. volunteered to serve as librarian for literature and educational material on PD available for members of the group to borrow.

There was a general discussion of various issues such as diet, eating habits, difficulty in sleeping and the progression of PD.

Future meetings will be scheduled on the third Saturday of January, April, July and October. The next meeting will be held at Haviland Hall on Saturday, January 19, 2002 at 1 P.M. The entire meeting will be devoted to discussion of the educational initiative and other issues participants wish to bring up.

The meeting adjourned at 3:30 P.M.

Respectfully submitted: **Lou S.**

SOMETHING OLD, SOMETHING NEW

Roger B. was diagnosed with Parkinson's Disease over 16 years ago. Jeff Lincoln was diagnosed last year. Both men are in their mid fifties. The aim of this interview was to pass some of the lessons that Roger has learned on to Jeff.

J: How long have you had PD?

R: 16 years

J: What was the first symptom?

R: The first symptom was trembling in the right arm and my arm hanging down, like it was glued to my right leg when I was walking. When I stopped walking, it started trembling. I'd match beat with Diesel trucks and stuff.

J: That's interesting. My first symptom was my left arm hanging down.

R: It usually starts on one side or the other. The left side, caught up on me.

J: How did you find out that it actually was Parkinson's Disease?

R: Well, I first went to the Emergency Room, and I got the Doctor who delivered my sons. She called in Dr. ___ who I used when I crashed my brother's car. He checked me because I blacked out, couldn't find anything then. His office gave me a lot of runaround, so I finally went to the Lahey Clinic on December 23, 1986. I got the head doctor at the Lahey clinic, in neurology, Dr ___. He had me do a couple of things, and he says "you have Parkinson's Disease". That's how I got diagnosed.

J: How did you feel when you were first found out?

R: I didn't know what to think.

J: Were you scared?

R: No, I didn't know enough to be scared. I went to my boss after that and told him I had Parkinson's Disease. And he says "You're taking it awful lightly", and I says "What do you want me to do? I've got to learn to live with it."

J: Where were you working at the time?

R: Electric Boat, as a second shift foreman for tanks and topsides for all the submarines in the yard. I had more responsibility than any other boss in the yard at the time.

J: Did the job require a lot of strength and agility?

R: A lot of walking. I had to go from one end of the shipyard to the other 2 or 3 times a night.

J: When you were walking with people, would they notice if you were walking funny?

R: At times my right leg would go sort of dead on me. I'd start dragging it. People would ask me if I did something to my knee or hurt my ankle. I'd say "No, I got Parkinson's Disease". They'd say "Well, I'm sorry to hear that". And I'd say "I don't want you to be sorry about it. It's not your fault".

J: My biggest fear was that people would treat me different.

R: The first thing that you learn about being handicapped is that people want to treat you differently, and you find out why the handicapped always wanted to be treated like anyone else. And you remember back when you were dealing with handicapped people, and you say "Boy was I such a fool."

J: So you told people right away? I lied for a while.

R: A lot of people do that. It's a personal thing.

J: You kept working after you were diagnosed?

R: Yes, from December '86 to January '92. The first year I tried to cut back on overtime, then I just went back to a normal schedule, being the sickest guy in the department but working the most hours.

J: I guess that comes with the supervisor's job.

R: Yeah, If I was working five days, I was working 50-55 hours. Sometimes I worked 6-7 days.

J: What other changes to your lifestyle did you make?

R: At first none; I didn't change anything. I tried not to. Eventually it takes over and changes you. I got a friend who says, "We may not win the battles, but there's joy in the fight."

J: A lot of people with PD have anxiety or depression. Do you?

R: They said I had depression, but I didn't think so. I kept a good sense of humor about it. I guess I get a little depressed at times, I don't make a habit of it.

J: It's the most important thing for me now, and I take medication for it. Let's talk a little bit about medication. When you were first diagnosed, did you go on medication right away?

R: Yeah. Back when I was diagnosed, the only treatment was to put you on high doses of Sinemet. That was the only drug available. Agonists didn't come out until a year or two afterward. I was started at four tablets 25/250 4 times a day.

J: So when you came back from the Lahey Clinic, did you have to find a local neurologist?

R: Yeah, There were only two groups in the area, Norwich and New London. I'd already been through the New London group and I didn't like their office etiquette, so I called up and got an appointment with Dr. ___ in Norwich, and I've been with him ever since. This guy's theory was "less is more". His first action was to try to cut back on my medication. I'm still not back up to where I was. He's of the opinion that I'm at the last qualitative change I can make without getting into problems. We went down to Mt. Sinai last week. I was taking a half a Comtain with each dose, and they wanted me to take a whole one so I'm going through it, but I think it will cause more dyskinesia.

J: Tell me about Deep Brain Stimulation?

R: I went down there for an evaluation of DBS. That'll be sometime down the road if I do it at all.

J: Do they look for a certain stage of PD and then you become eligible?

R: Yeah, you have to be at Stage 3 or 4, and they do it at Mt. Sinai and NYU. They got a much better screening process than some of the other places.

J: Have you been on any clinical trials?

R: No, the last time I asked about a clinical trial, they said I'd been on Sinemet too long.

J: Tell me a little about your hobbies?

R: My hobbies are fishing and woodworking. I built the dry sink and that table, the angel there and the Indian chief. It takes me a lot longer to do them now than it used to. I get dyskinesia down there and I start falling into things. I get tired.

J: I understand. Even at my earlier stage, it just takes longer to do everything.

R: I'm one that believes in pushing the envelope as far as it will go. I've seen a lot of people who have progressed a lot faster than me. It's my attitude. Attitude is everything.

J: It has struck me that you're in terrific shape for having had PD for 16 years.

R: I try hard.

J: What advice would you offer a person like me who has been recently diagnosed?

R: Don't give up anything until you have to and keep pushing the envelope as far as you can go. The only thing I gave in to was driving because I could hurt other people besides myself. You got to fight it; it's a war. It comes down to what you can hold onto and how long. It's not a death sentence, but a career.

J: Thanks for spending time with me. I've learned a great deal.

The Parkinsonian Personality: Myth or Reality?

By Toni de Marcaida, M.D.

The first time I met Stan (Wertheimer) and Jackie (Dorwin), we chatted freely about Parkinson's Disease (PD), the various clinical research activities ongoing for PD, and how much I enjoyed being with the PD community and support groups. Then of course, they had to come up with a question that left me groping for words: "Why are you so involved in PD?"

I didn't know quite why. I just knew that I was happy when I was caring for and hanging out with my patients who had PD. I loved the people. I loved the families. We would frequently become friends. "Because PWP are just such a wonderful bunch of people!" was the only rather lame reply I could come up with. Not too impressive an answer for someone who is supposed to be an "expert parkinsonologist".

Truth be told, I have not been in this business for very long. I did my neurology residency training here at the University of Connecticut not too long ago. That was my first opportunity to care for someone with PD. She was an elegant lady, always well dressed and extremely gracious. She was a bit anxious about her condition, and she called me constantly, but I so enjoyed talking with her. I would reassure her, and try to help her with the troubles with which she was just coming to grips. When reassured, we would go on to chat about other things: the latest show that was playing at the Bushnell; the last art exhibit she had seen; the interesting people she and her husband had met at a party the night before (She met Janet Reno, and talked about PD with her!); her horrible score at the golf game last week. Then we would talk about PD again, and what we can do to optimize her "on" time. Our relationship was that of doctor and patient. But I hoped that for her, as it was for me, we were also friends.

After residency, I went on to do a subspecialty fellowship in movement disorders and clinical research. By this time, I had had a couple of years of caring for people with PD, and I had decided that this specialized field is where I wanted to be for the rest of my career. I had found that I had yet to meet a PWP whom I did not like. I was intrigued by the condition, challenged to try to help. Why? Because PWP are just such a wonderful bunch of people.

I am not alone in saying that patients with PD seem to have a distinct personality. Medical literature from as early as 1913 described parkinsonian patients as industrious and moralistic. In 1942, Sands, in an article in the Journal of Mt. Sinai Hospital, postulated that certain personality traits, specifically superior intelligence and emotional suppression, made PD patients susceptible to developing the condition. Then in 1948, Booth described the typical PD patients as successful, independent, responsible, assertive, and law abiding. They frequently enjoyed a satisfactory and stable married life. Many years before the development of the disease, in fact as early as 8 years of age, patients who eventually developed PD were observed to be more

quiet, self-controlled, less aggressive and adventurous. This was reported in a study describing the personality traits of twins, one of whom developed PD later in life. Patients with PD are also more frequently non-smokers.

Subsequently, as clinical research became more sophisticated, parkinsonologists were no longer satisfied with just descriptions and random observations regarding this phenomenon of a distinct pre-morbid personality type (i.e., personality traits observed even before the development of the disease) in PD. More recent studies therefore made head-to-head comparisons between patients with PD and those with other medical illnesses (e.g., rheumatoid arthritis, essential tremors, orthopedic problems) or healthy controls. The groups were subjected to a variety of questionnaires and surveys designed to determine if there was a difference between them as regards personality traits and pre-morbid lifestyles. Lo and behold, the results of these studies were compatible to the observations of earlier years: PWP are more cautious, less flexible, and more conventional; they are driven, socially alert, self-reproaching, tense, apprehensive and skeptical; they had less “novelty seeking” behavior than patients with other medical conditions. A person with less novelty seeking behavior was defined as someone who was reflective, rigid, loyal, stoic, slow-tempered, frugal, orderly and persistent. Characteristics perhaps, which are a formula for success in life, stable marriages, and social acceptability? Or characteristics which result in the development of PD?

Are any of these related to dopamine, the chemical which becomes deficient in patients with PD? Does this moral uprightness deplete dopamine in early life causing PD to develop in later life? Or is it in fact that having relatively less dopamine, even in childhood, is the reason for this stoic, non-adventurous type of personality?

To this day, investigators are not convinced that we can sort out what is fact and what is fiction. They are not convinced that we can show, in a scientific manner, that there is a real association, whether as a cause or an effect, between specific personality types and PD. They seek more stringent and more scientifically sound study designs to prove or disprove this hypothesis.

As for me, I am happy simply to say that I enjoy being with the Parkinson’s community. I am comfortable in the company of morally upstanding, intellectually stimulating, loyal and dependable friends. It is a privilege to have the opportunity to care for them. It is a privilege to be counted as one among their friends.

Happy holidays to all. Peace to people of good will.

SOME CRAZY IDEAS

by Jon B.

I happened to come across this:

... the definition of a specific parkinsonian personality developed from psychoanalytic thinking in the first half of this century. These studies described the prototypic patient as introspective, emotionally inflexible, well controlled, and predisposed to depression. Before motoric signs of PD appear, these patients tend to be law-abiding citizens, diligent, trustworthy, and often lacking in self-confidence or willingness to take risks. Studies of twin pairs, one with and one without PD, revealed the affected twin, even as a child, to be the more likely to be self-controlled and a follower.¹

When I read it I wasn’t happy. It seemed to say that parkinsonians are people who are Obsessed With Rules.

Now I wouldn’t ordinarily take this sort of thing very seriously. Nevertheless, I think of my parkinsonian father who never used his expense account for fear of stealing a penny from the company. (When I lived in Africa I didn’t work the black market. I had barely enough money to feed my family, but I wouldn’t break the local laws.) And I think of my student’s parkinsonian father who each day rearranges the tools on his bench, but who never makes anything. (My desk is neat, but I’ve never written a book.)

In fact, whether I like it or not, I fit the profile. And that gets me to wondering: *maybe diseases get the people they deserve; maybe, for example, evil diseases get evil people, good diseases (whatever good diseases are) good people, and diseases in between (like PD) people who (like us) are, well, complicated.*

Now that's a Crazy Idea (Crazy Idea Number One). I mean it's an idea which I have no good reason to believe, and which I probably never will have any good reason to believe. Nevertheless, I believe it.

Now Crazy Ideas are always popping into my head. Here's another one (Crazy Idea Number Two): *maybe parkinsonians are people who get Crazy Ideas; maybe getting Crazy Ideas is part of the parkinsonian behavioral profile.*

In that case, however, why did the psychologists miss it? Because, in the first place, behavioral psychologists don't believe in Crazy Ideas—not the kind, at least, that come out of the blue. And, in the second place, these particular psychologists were looking for a pattern, and having Crazy Ideas doesn't fit the pattern of being Obsessed With Rules.

All right then, what *is* the relationship between being Obsessed With Rules and having Crazy Ideas? Let me think. Well, yes, I have an idea about that, too.

Suppose I have a resting tremor. The opposing muscles in my arm fight each other. Like a furnace with a faulty thermostat, my arm oscillates out of control. If it could escape its skeletal restraints, it would fly off. My arm is paralyzed by an Obsession With Rules (metaphorically speaking, of course).

Now I see an apple on the table. I'd like to eat that apple. My arm has a Crazy Idea (again, metaphorically speaking). It stops oscillating. It reaches out, smoothly, purposefully. It grasps the apple. It brings it to my mouth.

My arm, then, has passed from one state (being Obsessed With Rules) to an entirely different state (having, and acting upon, a Crazy Idea). Being Obsessed With Rules is characterized by rigidity, inaction and lack of meaning. Having a Crazy Idea is characterized by fluidity, freedom and sense of purpose.

Now it occurs to me that maybe non-parkinsonians have these two states mixed up: every movement is the expression of a habit *and* the pursuit of an idea. The habit is not an obsession because it has a purpose. The idea is not crazy because it conforms to a rule. *In parkinsonians, however, the states are separated. The habits are obsessions (in their purest form, catatonic states). The ideas are crazy (in their purest form, revelations)* (Crazy Idea Number Three).

So what's the point? Probably none. But, at least, some advice: *Hold on to your Crazy Ideas. Cherish them. Believe in them. Because Crazy Ideas can give fluidity and purpose to the movements of body and soul* (Crazy Idea Number Four). Besides I'd sure like to prove those psychologists wrong.

1. Goetz, Christopher G., "The Historical Background of Behavioral Studies in Parkinson's Disease," p. 7 in *Parkinson's Disease: Neurobehavioral Aspects*, ed. Steven J. Huber and Jeffrey L. Cummings, New York: Oxford University Press, 1992.

Considerations for PWP When Hospitalized

by **Steve Holahan**

I spent 3-4 days in Hartford Hospital with pneumonia in 1992. At that time I was taking Sinemet, Sinemet CR, Eldepryl, Artane, Symmetrel, and Parlodel plus vitamins E and C. My focus will be on an unplanned hospitalization and what to do about medications.

Multiple copies of your meds list, neatly typed with correct spelling of drug names, pill size or strength, and your dosing schedule will save you a lot of time and ensure accuracy during hospital admittance. In addition include the name and phone of your various doctors, your pharmacy and your spouse/caregiver. Add an emergency backup contact. The PC makes keeping the list current easy and lets you shrink the list to wallet size for emergency situations. Laminate it between two pieces of clear packing tape to ensure its readability.

If possible take a supply of all your meds to the hospital; they may add a big markup for meds from their pharmacy. However there may be cases where your meds are covered by your hospitalization; if you have no Rx coverage, it would make sense to leave your pills at home. Hospitals will not supply vitamins (unless prescribed by your doctor), over-the-counter items, and other "health-food/witch-doctor" tonics. Once the supplier of the meds is established, day to day control of the meds (what to take and when) must be decided

upon. Usually the hospital likes to do this, and depending on the reason for the hospitalization it may be the only option. In my case, after the first day in the hospital the pneumonia and high fever were controlled and I was up to the task.

In addition, because I did not have a neatly typed list of my meds ready at admittance, the hospital had yet to get a "pill session" right! So always double check anything you get in those little Dixie cups.

Having focused all this attention on meds, they will not perform as advertised, nor will your PD. A hospital stay is a stress producing change to our daily routine. Our diet, sleep cycle, and exercise pattern change and we have a sick or injured body to contend with. So as is always the case with PD-try to be flexible-----literally and metaphorically!

Parkinsons and Constipation

For twenty-four years Robert Abbott, at the University of Virginia, Charlottesville, and his research team followed the medical history of 6,790 men living on the island of Oahu, Hawaii. They found that men who reported persistent constipation (defined as having an average of less than one bowel movement per day) were: 2.7 times more likely to develop Parkinson's than men with an average of one bowel movement per day; and 4.5 times more likely to develop the disease than men with more than two bowel movements per day. The data were adjusted for dietary and environmental factors including age, smoking, coffee consumption, laxative use, jogging, and intake of fruits, vegetables and grains. This did not alter the team's findings. Dr Abbott said that this finding should improve our understanding of the progression of the disease and help to identify people at risk. He commented that the same processes that cause the motor symptoms of Parkinson's may also affect the colon's functioning and there may be abnormalities in the muscles involved in bowel movements. Further work is needed to discover whether constipation influences the development of Parkinson's; or is a disease marker linked to other genetic or environmental factors that make for greater susceptibility to developing the disease. People with constipation which does not respond to laxatives, and who have other factors such as a family history of the disease, may be at higher risk.

Source: New Scientist (14 August 2001) and Neurology (vol 57, pp.456-462)

When Parkinson's Strikes Early

"**When Parkinson's Strikes Early: Voices, Choices, Resources and Treatment**" by Barbara Blake-Krebs and Linda Herman (both American PWP) was published in September 2001 by Hunter House Publishers, of Alameda, California.

This book presents all aspects of life with PD, as experienced by young onset PWP from around the globe. Their email conversations from the *Parkinsons* mailing list, life stories, essays and poetry have been woven together with patient-oriented information on diagnosis, treatment and self-help options. Extensive resource listings and ideas for grass-roots advocacy are also included. The focus is on empowering People with Parkinson's.

This book would be of special interest to the newly diagnosed, their families and friends, health care personnel who work with Parkinson's patients, those dealing with other chronic illnesses, as well as anyone who wants to know more about PD. The authors' undertook this 2 1/2 year project in order to raise Parkinson's awareness. All authors' royalties are being donated to programs that fund Parkinson's research, improve the quality of life for PWP and their caregivers, or enhance public awareness about the disease. This book was reviewed by Emma Bennion in the recent Parkinson's Disease Society Magazine

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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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