

Connecticut Parkinson's Working Group Newsletter

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RECENT GIFTS TO CPWG

This space will contain acknowledgement of gifts to the CPWG and, if specified, who the gift honors.

We gratefully acknowledge a generous gift made by Ruth (Wertheimer) Manson for support of the newsletter for one year.

INTERVIEW WITH WILLIAM F.

Jeff Lincoln 8-26-04

William F. is the Chair of the Political Science Department at Yale University and also a Person With PD

J. I understand that you are a Tenured Professor at Yale?

W. Yes I am. I've been here a very long time. I came as a Graduate Student in 1957 and joined the Faculty in 1963 in Political Science.

J. What is your specialty? What are you interested in?

W. My specialty is the politics of Africa.

J. That should give you enough material for 100 lifetimes.

W. It does keep me busy. I spent two weeks in Mali over the spring break. In that case I went as a member of the board a small non- governmental organization. I was over looking at some education projects. It's a part of my work that tries to do good. Most of my work as a Political Scientist is to try to explain evil!

J. You have just become the Chair of the Department of Political Science?

W. Yes, I got talked into it because it is only a oneyear sentence. I had been Chair once before, about twenty years ago. I agreed to be Chair for a year, after which, it's time to bring on another generation.

J. Every time

I

interview someone with

Parkinson's Disease (PD), I go through a few standard questions. What was your first symptom?

W. I had a tremor in my left leg. I'm not sure when it started. It was really my wife Anne Marie who brought it to my attention. I told her it was just a little thing. And then the tremor got more frequent and more vigorous, and I saw my Primary Physician at the Yale Health Plan, and he referred me to Dr. _____ in the Neurology Department who decided that I did not have PD but did have an Essential Tremor. I had also been seeing a Psychiatrist for mild depression, and he said that it didn't it didn't look like PD. And so it

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didn't seem like PD, until things got worse. My wife, who can be a very effective and forceful person insisted we get a second opinion. I went through a series of very thorough tests that I suppose is the standard variety, everything from psychological to manual dexterity tests. I was then referred to Dr. _____. It was decided that, yes indeed, I had PD.

J. So you had this belated diagnosis of PD after being told that it was not PD?

W. Yes. The diagnosis came as a relief. It was a bizarre reaction, but at least I knew what was there.

J. I had an parallel experience with some of the same people involved.

W. I know now that I'm not alone and that medicine recognizes the disease even though I now know that medicine doesn't do much more than recognize it.

J. How long ago was the diagnosis made?

W. It was just about four years ago.

J. What are you taking for medicines?

W. Mirapex, Namenda (developed for Alzheimers but may be beneficial for PD), Paxil for depression.

J. So you are not heavily medicated?

W. No, Mirapex is the principal drug. I take it three times a day.

J. You are in what I think of as a fairly early stage, as I also characterize myself.

W. I'd like to stay at this stage.

J. For a PWP with a tremor, you seem to move and walk well.

W. Walking is fine except that I tore my Achilles' Tendon six months ago, but that's not a Parkinson's story. My natural default walk is slower than it used to be. I'm not sure if this has to do with PD, or to the fact that I'm sixty years old versus thirty years old. I used to walk faster than the undergraduates down Prospect Street, and that's not the case now.

J. Let's return to the subject of your Professorship and Chairmanship. It seems that one of the things that PWP's have to deal with is a lower level of energy. But you have two things in your life that require a lot of energy. How do you manage?

W. Let's see how well I manage to do it. There is no doubt that I am slower than I used to be and not as good at multitasking. I quite intentionally try to pare down the number of things I'm involved in, and shove off to someone else where I can. I'm not very good at that. I realize that I'm not going to turn out a lot of publications this year.

J. One of the first things that you have to do as Chair is a search for your successor?

W. That's true. I intend to be involved. I will urge President Levin to decide who is going to be in charge of the search for the Chair. We'll see if we can get that thing going earlier rather than later. Meanwhile we've got a lot of other appointments to attend with.

J. Are you going to do things differently because of PD?

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W. Well, I am a bit concerned. I presume we're going to make some senior offers this year which will mean defending those offers before the divisional committee and eventually the joint boards. I'll have to stand up and make a speech, and I've been thinking how I'll handle that. I may just use a cane. Just from having the solidity of having a three point stance.

J. I wonder if you could ask them if you could do it from a chair?

W. That's another possibility, just saying "I hope you'll excuse me if I sit down while I do this" and then whether or not they excuse me, I will sit down.

J. I gather that the department is one of the largest at Yale?

W. The second largest undergraduate major at Yale, and it's a growing department. We've had some unexpected and unfortunate losses. One young new hire at the tenure level was diagnosed with a brain tumor and they are operating this afternoon.

J. There are a lot of things worse than PD.

W. That is certainly true. But barring some miracle, I'm never going to get better. I think I've adjusted to that reasonably well.

J. Let's talk about the Yale Parkinson's Faculty Support Group. How did you contact that group?

W. I got it through Dr. ____ (Parkinson's Neurologist) at the Yale Health Plan. He had spoken to the group before I knew of it. I asked him (later) if he knew of any support groups, and he said yes! That was about a year ago.

J. Amore difficult question: What have you given up since being diagnosed with PD?

W. I don't run but that may be the Achilles' tendon more than PD. I can't think of anything else. I've cut down on my wine drinking, but I haven't cut it out. It's beneficial for lots of things including my mood. I've also cut down on driving and Anne Marie does more of it. She wants it that way. She does a lot more driving of the boat also. I've given up water skiing. Where I notice PD more now is waiting in line and pitching forward a little bit and knowing that I have to readjust the balance.

J. I find I still do almost all of those things I did before PD but so much slower.

W. The slowness drives Anne Marie up the wall, as I fumble and fuss putting together the cheese grater.

J. Do you have any advice for PWP's?

W. Good Question (pauses). My attitude is to try and do as much as I can and put up with some embarrassing moments of failure or observable weakness. I also decided that when I meet a new class, I tell them I've got a neurological problem. I've learned to live with and they should too. I didn't ever want to hide my PD. A week after I told one of my colleagues, everyone knew.

J. Anything more to add?

W. Be as much of yourself as you can.

J. Thank you for spending time with me.

W. Thank you, I enjoyed this.

VACCINE REDUCES PD NEURODEGENERATION IN MICE July 28, 2004

For the first time, researchers have shown that an experimental vaccine can reduce the amount of neurodegeneration in a mouse model for PD. The finding suggests that a similar therapy might eventually be able to slow the devastating course of PD in humans.

The experimental treatment in this study is among the first to show potential for slowing brain degeneration in this disease, the researchers say. Currently available therapies can treat symptoms of the disease, but they do not prevent the loss of brain cells.

"This is a novel therapeutic approach to stop the damaging inflammation associated with neurodegeneration. It is exciting because an approach like this may be beneficial in a variety of neurodegenerative diseases in addition to PD," says Diane Murphy, Ph.D., a NINDS program director for PD research. The research was funded in part by the NINDS and appears in the June 22, 2004 issue of the Proceedings of the National Academy of Sciences (PNAS).

Studies in the last decade have shown that inflammation is common to a variety of neurodegenerative diseases, including PD, Alzheimer's disease, and ALS or Lou Gehrig's disease. The inflammation in these diseases involves activation of microglia—specialized support cells in the brain that produce immune system signaling chemicals called cytokines. Although inflammation can be damaging, Michel Schwartz, Ph.D. and colleagues at the Weizmann Institute in Rehovot, Israel, have pioneered research that shows activating immune

cells in specific ways also may lead to neuroprotective responses in animal models of spinal cord and brain injury.

In the new study, Howard E. Gendelman, M.D., of the University of Nebraska Medical Center in Omaha experimented with a drug called copolymer-1 (Copaxone). Previous studies have shown that Copaxone, which is commonly used to treat MS, increases the number of immune T cells that secrete anti-inflammatory cytokines and growth factors. The researchers took immune cells from mice that had received Copaxone immunization and injected them into mice which had received injections of a drug called MPTP. MPTP leads to PD-like neuronal degeneration in the brain.

Mice that received the Copaxone-treated immune cells had significantly less degeneration of DA-producing neurons in their brain than mice that did not receive the treated cells. These mice also lost fewer DA-transmitting nerve fibers than control mice and had only a small decrease in the amount of DA produced in the brain. DA is a nerve signaling chemical (neurotransmitter) that controls movement; a loss of DA-producing neurons is the central problem in PD.

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The researchers found that T cells in the treated mice migrated to the damaged area of the brain, reduced the harmful reactions of the microglia, and triggered a neuroprotective response. In addition, the vaccine dramatically increased the amount of a growth factor called GDNF (glial-derived neurotrophic factor) that helps prevent neurodegeneration.

“This study provides a proof of concept,” says study coauthor Serge Przedborski, M.D., Ph.D., of Columbia University in New York. The vaccination modifies the behavior of the glial cells so that their responses are beneficial to the nervous system rather than harmful, he explains.

The researchers injected Copaxone-treated cells in this study because MPTP destroys the mouse immune system, Dr. Gendelman says. The MPTP mice needed replacement immune cells in order to respond to the drug. However, Copaxone could be given to humans directly, he says. The researchers are now planning follow-up studies to confirm their results and to identify the specific cytokines, nerve growth factors, and other proteins that play a role in the protective response. Other work is needed to determine how to translate the study results into a therapy for humans and to make sure the treatment is safe for patients with PD, who may not react to the drug in the same way that MS patients do.

While Copaxone is currently approved by the U.S. FDA for use in treating MS, the dose needed to treat PD will probably be quite different from the dose used in treating MS, says Benner. The timing of treatment may also prove critical. Therefore it is premature for patients with PD to begin taking the drug. Currently available doses of the drug could be ineffective or even harmful for PWP.

—By **Natalie Frazin**

A NOTE FROM DR ABE LIEBERMAN TO HIS WEBSITE AT NPF SUN, 31 OCT 2004

Last week I met with the people at Schwarz Pharma; I learned that the information on the DA patch is impressive. The data have been submitted to the FDA and the European equivalent of the FDA. Schwarz hopes to have the patch available in 2005.

From Vienna I went to Salzburg to a meeting entitled Mental Dysfunction in PD. There were three days of excellent papers. The highlight was a debate between Dr Heiko Braack, one of the world’s foremost neuropathologists, and Dr Kurt Jellinger, the “king of neuropathology”. Dr Braack, after 20 years of meticulous study [postmortem] of brains of PWP at different stages has shown that PD begins NOT in the substantia nigra but in a region called the dorsal vagal nucleus; this is the head of what is called the parasympathetic nervous system, that calms us. Next involved is called the locus ceruleus, a region involved in alertness and in regulating sleep. Another region involved in sleep is also affected which may be why sleep problems are so common in PD. Next the substantia nigra is involved; later on structures involved in mental processing are affected. Last year Dr Jellinger confirmed these findings.

Dr Braack believes that the dementia of PD results from a continued loss of cells from the same process that affects the substantia nigra; Dr Jellinger believes the dementia results from Alzheimer type changes. There was a spirited discussion. The differences may be in the patients they are seeing; Dr Braack gets his brains from people who die at home or in medical hospitals; Dr Jellinger gets his brains from more advanced patients who die in a chronic care institution rather than at home.

NEWS: We are pleased to announce the marriage of our newsletter designer Alyssa Wertheimer (now Morin) to Eric Morin on 30 October 2004 at the O'Neill Center in Waterford, CT.

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MEETINGS ON THE MOVE (MOTM)

Jackie Dorwin

Several people expressed concern about those who want to come to our CPWG meetings

but are unable to. The factors affecting attendance seemed to be the person's health and carepartner's health, the weather, driving distance to Middletown, and the topic of the meeting.

For each factor there's not much we could change. So where did that leave us? We looked at each factor again and realized that travel concerns could be addressed: if people can't come to the meeting, maybe the meeting can go to them. After brain-storming we decided to try MOTM—to bring the support, information, and understanding of CPWG to PWP in all areas of Connecticut. The state is divided into quadrants; a meeting will be held in each quadrant once a year. The meetings will not take the place of the regularly scheduled meetings in Middletown, but will be planned for four months when we do not have a Middletown meeting.

We felt that October would be a good month to try out this new program and with the wonderful help of Dave Curtin, our first MOTM was held in Newtown at the Cyrenius H. Booth Library on October 16. Dr. John Murphy of Danbury was our guest. In evaluating the success of our new venture, we used the unscientific notions of the number of attendees plus the number of positive post-meeting comments equals the degree of success: we had 46 attendees and an abundance of positive feedback. Our new program was judged successful.

The potential of this program for outreach and the excitement it has generated already have us feeling good; however, reality cautions us to slow down. Proceeding with this program will almost double the number of meetings we hold, and will increase our expenses and corresponding responsibilities—additional postcard mailings, meeting planning, healthy snacks, mailing list adjustments, phone calls, postage, and so on. While all this is manageable, we will need help both in the form of workers and donations.

We need to identify specific places to hold a meeting, and the services of someone who can find a meeting place, distribute flyers, put notices in the newspapers, and help out at the meeting. Our next MOTM will be February 19, 2005 at the Gables in Farmington beginning at 12 noon. More information will come via the meeting reminder postcards. In April we will be in the Mystic-New London area.

PERCEPTIONS

Stan Wertheimer

What affects us is not what is true, but what we perceive. I started thinking about this recently in relationship to PD. In considering what we perceive we must take into account what is the truth, be it known or unknown, our knowledge of the situation, our experiences, our prejudices, the influence of others, and our ability to synthesize a conclusion from all of these input factors. The more I thought about it the more daunting the topic became. However, I felt it was worth the effort, albeit a potentially flawed one. The focus of my thinking was to explore the differences between the "truth" and our perceptions of the truth.

In regard to PD there are many people whose perceptions matter to us: our life partner, our children, our grandchildren, our friends, our doctors, and, of course, ourselves. Also, perceptions change with time, as PD changes and as we, and the people around us, change. It is the perceptions we react to and over which we feel we have some control. This is clear if we think about the situations where we know the truth is that we have PD and we spend our time and effort trying to do the things we think we have to do to keep certain people, such as those with power over our employment status or those we might be trying to impress with our robustness, from knowing that we do. That is, we do what we must to make outward perceptions appear to be truthful evaluations—robustness versus PD. This can be work. If we try to fool

those closer to us we could be doing some real damage in the areas of trust, affection, and love. If we try to fool ourselves it is called denial.

There is the time before we are aware that we have PD. We may know little or nothing about it, and the same for the people in our lives (unfortunately, there are neurologists who fall in this category). When we saw a stooped person with a noticeable tremor did we think less of that person? Did we pity her/him, or dismiss the person from our awareness? Perhaps, as was the case with my mother (who had early onset PD), my family got a worse case picture because of the severity of her PD and the lack of good options at the time (1950s). I know that when my relatives heard that I also had PD (1990) they pretty much figured that that was it for me—no future. Who can blame them for that perception, given their experience with my mother and their lack of current knowledge. This is a place for those of us with PD to provide education for the people around us so that when one of them either is diagnosed with PD or encounters a person with PD they will have a more realistic and accepting attitude. It is the old

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story—one should not equate a person with that person's disabilities (is that a non PC word?). I once suggested to a woman, who had lost both eyes to juvenile cancer and gone on to raise a family with two children while holding a job running a small coffee shop, that blind people should not smoke in bed (ignore the question of smoking at all for the moment). She read me the riot act! In essence she told me in no uncertain terms that a blind person could do anything a sighted person could; how could I argue with her? I was making her into her blindness, and she was having none of it.

The next stage is when we are first diagnosed. Reactions vary as to how we perceive our new status. I have spoken with those who felt that their life was severely compromised even though they had no idea where the disease was to take them. There are those who accept and immediately try finding out more so that they can be partners with their physician in treatment. Others deny the facts and seem to carry on as before, while some are stunned and find that they don't know what to do. I imagine a lot of the way a person reacts is personality based, and part is due to previous perceptions, if they had any, of PD. One question is: how does the perception of the newly diagnosed person change in the minds of those around him/her? Once one has PD perception changes are incremental and usually small since PD is a slowly progressive disorder; however, the change from not knowing to knowing is major. When I told my colleagues at work that I had been diagnosed with PD one of them immediately asked if I was still driving. He knew I was fine to drive the day before but somehow the new knowledge, in his mind, might have made me feel that I could no longer drive, one day later. Others at work seemed to forget that I had PD while some treated it as a slowly progressive chronic disease and from time to time asked how I was doing—the approach I most appreciated. I know my perception of actions by those around me was newly tempered by the concern that they had found out that I had PD and were taking that into account in their behavior toward me; I felt that I should be treated the same, and, most often, probably was, although I clearly became slightly paranoid. By the way, my reaction to being diagnosed surprises me to this day in light of my family history: I felt no real concern and was, if pressed, certain I could deal with the future. Whether that attitude was correct remains to be seen.

Then comes the usually long period of changes in one's physical and mental abilities due to both PD and aging. There are also changes in one's needs and desires due to the same factors. Perceptions can remain constant over long periods of time, or change gradually as one's abilities gradually change. I opt for the former—I think most of the people whose perceptions we care about feel that we are the same until they see a clear difference; that is, their perceptions have a builtin buffer which smoothes over any change but those which exceed a certain magnitude. For example, a friend may go from thinking of you as a well person until he/she notices several situations where it is clear you have a chronic disease, after which you are perceived to be a PWP, with no transition from well to slightly impaired to noticeably impaired to a PWP. You may feel the changes gradually occurring and be surprised that not everyone can see the same changes, not even your neurologist. Is it that the people around you really don't notice or is it that their expectations of you have been permanently diminished so when they see a negative change their brains say "oh yes, he/she has PD and that is to be expected—no need to modify my thinking on this person"? In the case of your neurologist that person may see so many people with serious deficits that your small changes don't register or it may be our perception that he/she doesn't notice while actually she/he does but didn't think the change was significant enough to mention.

How do I want to be perceived vis-à-vis PD? A while back I would have said that I would like to be seen as a person with no noticeable symptoms and hence a person free of PD. This, friends, is pure vanity speaking. I am now more realistic, as well as more symptomatic. I suppose I would like to be seen as a PWP who is trying to control what he can and who accepts what he cannot control. Now all I have to do is live up to this goal as well as work hard trying to control what I can.

I perceive that this is getting a bit long for the newsletter, although I have barely scratched the surface. I will leave it here with the hope that there is enough to start some crosstalk among readers as well as reinforce the widespread need for the dissemination of information about PD.

HELPING THE CPWG

Again this year we are going to suggest a painless way to help the CPWG achieve some of its goals. First let's outline what some of those goals are:

- design and support a website. Skip K. has a start on this but much more needs to be done and it requires more than we have too spare at present. We would put notices of meetings, a copy of all newsletters with search capabilities, photographs, cancellations due to weather, links to other interesting sites, a place for PWP and others to write comments which can be globally accessed, special events, and other useful items;
- support guest speakers;
- support our outreach initiatives, such as our information sessions for professionals, which has been very well received, and our meetings on the move;
- purchase equipment such as a PA system, video capability, projection capability;
- support travel to important meetings, such as the yearly Parkinson Action Network meeting and the biannual Sturbridge meeting.

You can help with these efforts by simply telling those who give you (often unwanted) gifts at holiday time that your preferred gift is a (tax deductible) donation to the group that adds something positive to your life, the CPWG. Some of us already do this and have found that our loved ones listen and feel good about the choice. If they still want to give you something else they can split their gift. We are set up to acknowledge all gifts in this newsletter with as much, or as little, detail as you wish. Send all donations (deductible from federal income tax) to: Steve Holahan, Treasurer CPWG 20 Franklin Lane Glastonbury CT 06033

CPWG WEB PAGE

Skip K.

<http://www.cpwg2000.org/default.asp> will get you to the newest version of the website I have been working on. You can also get a feel for the rest of the site. We would greatly appreciate it if you fooled around a while and sent us your comments. We are looking for a few souls to work on individual pages of the site; that is, provide text to flesh out the various pages. If you are interested contact either me, or Stan.

PARCOPA

Erica G. Bradley

Schwarz Pharma Representative

Parcopa, an orally dissolving carbidopa/l-dopa (to be taken without liquid; it dissolves in 10 seconds; it acts like sinemet)), has recently been introduced by Schwarz Pharma. We have supplied all Connecticut neurologists with vouchers for 120 tablets at no cost to the patient; they are valid through 31 January 05 and you may obtain multiple vouchers. After this Schwarz has made available \$20 discount certificates, for a 30 day supply, which will be available indefinitely.

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DISCLAIMER:

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

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Write your Representatives in Congress!

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