

Connecticut Parkinson's Working Group Newsletter

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In addition to these CPWG received 50 other gifts from our friends and members; we wish to thank all of you for your generosity. Remember it is never too late to help CPWG continue its good work. If you have not yet given, please consider doing so now.

Checks made out to CPWG should be mailed to:

Stephen Holahan, CPWG Treasurer
20 Franklin Lane
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A REPORT ON OUR LAST REGULAR MEETING—15 JANUARY 2005

Stan Wertheimer

We met at a new location, the Middlesex Hospital in Middletown, which will be our permanent site for the foreseeable future. The final attendance was around forty. We had two short presentations, both passionate and fascinating.

The first was a plea to support a bill in the CT legislature to fund stem cell research in the state using donated embryos from various sources. This goes beyond what is federally accepted, which is considered woefully inadequate and inimical to good research by most people involved. The presenter was Bob Mandelkern, state representative

of PAN (Parkinson's Action Network) and APDA, who was eloquent and impassioned in his advocacy. He explained how safeguards were built into the bill to prevent most questionable uses of embryos. His bottom line was: write your state representative and senator to tell each how you feel about the issue. Of course, his hope is that your letter will be to support passage.

The second presenter was Terry Deshefy-Longhi, carepartner of John Longhi and a candidate at Yale for a PhD in nursing. Her topic was body language in the PWP and how it can fool

you, even if you are married to the person. More generally, she discussed communication issues and how body language and facial expressions in particular changes as PD progresses—it becomes less reliable, to the point of not being a trustworthy indicator at all. Her talk was an excellent introduction to and exposition of the issues.

Perhaps the most surprising moments of the meeting came when a new member, Bill G.

and his wife Karen, shared an experience that their family had gone through. It came up during the so-called “open” part of the meeting, where we feel free to discuss anything that has been on our minds. Bill has been diagnosed for six years, has been a responsible member of the community (a police officer) and a good father and husband. He added Mirapex to his medications and increased the dosage to get the best level to deal with his symptoms, as most of us have done with our meds. What happened next is a horror story, and took great fortitude to tell.

Bill became much more compulsive than his personality would predict, doing jobs around the house that required great determination and attention—such as painting all the rooms. Unknown to anyone he also started going to the casino to gamble. Over a period of time he won \$170,000; unfortunately he also lost \$200,000. I will stop there and leave the rest for an upcoming interview with Bill

by Jeff Lincoln, where the details will be discussed. As one can imagine, this led to an animated discussion of medication and its side effects and contraindications.

At the beginning of the meeting Steve Holahan, CPWG’s treasurer, had some superb news: our latest fundraising initiative (really, our first, spear-headed by Steve) was a huge success and continues to be so. We raised over \$4000 in two months, thanks to the generosity of many members and their families and friends. We will be acknowledging these folk in the newsletter.

Another report by Skip K. was more good news; he has a working web site up and running. The URL is www.cpwg2000.org. He will continue to refine it; however he needs some helpers, who can be anyone who is willing to put in a little time, but need not know anything about web sites and such. Please consider working with Skip—it can be fun, and will certainly be of great use. He will explain his need to you if you contact him, or just go to the web-site and follow instructions.

The consensus was that this was a special meeting, with the certain knowledge that there will be many more of this caliber. The reason was clearly that it involved our own members doing their own thing and being willing to share with the rest of us. It was a great experience.

THE FEBRUARY MEETING ON THE MOVE

Jackie Dorwin

Stan asked me to give an accounting of our February 2005 meeting for this newsletter. Every time I think about that meeting, I shake my head in disbelief. Last October we were invited to use The Gables at Farmington for one of our meetings. What a wonderful invitation; it fit in nicely with our new idea of “meetings on the move.”

Our plans called for a panel discussion, lunch for the attendees, and no snow that Saturday. The staff asked us for an estimate of how many would be attending as they were providing lunch for us and they needed an approximation for their chef. Our guess was 35-40. That’s what our meetings had been running and why would this one be any different? So we went along, advertised, talked about, planned, and waited.

Then it came time for the RSVPs to start coming in. Thirteen came the first week. Thirty and we were feeling pretty good about our estimate. Forty-five and we were a bit surprised to have this number so soon. Sixty came and went quickly, and when we reached 80, we hoped that the dining room would be large enough. Our final tallies were: RSVPs: 108. Actual attendance: 102.

The core of the meeting was the panel discussion on “Perspectives on Parkinson Disease.” Scheduled to speak were Dr. Rowena Tabamo, a neurologist and PD specialist with the Institute for Neurodegenerative Disorders; Sheila Belber, RN and associate director of the movement disorder center at the UConn Health Center; and Jeff Lincoln, PWP and willing speaker.

Rowena and Jeff did an admirable job presenting their views and answering the wide range of questions posed to them. Unfortunately Sheila could not attend but she has promised to come to a future meeting.

There seems to be a real thirst for knowledge about everything Parkinson's, and those who

came to this meeting appeared to be satisfied. It encouraged those of us who plan the meetings to continue our efforts. We also came away from that experience with a new gratitude for the staff at The Gables and their graciousness and flexibility in having us there.

APRIL'S MEETING ON THE MOVE

We will have a meeting, on Saturday, April 9, 2005,
beginning 12:00 p.m. at the Baker Auditorium,
Lawrence & Memorial Hospital, New London, CT.

*The guest speaker will be Dr. J. Antonelle DeMarcaida,
a Hartford Hospital & UConn Medical Center based neurologist,
known for her deep concern for patients, and her involvement in Parkinson's Disease research.*

INTERVIEW WITH JIM W. by Jeff Lincoln

11/06/2004

Jeff: There are a few questions that I always start out with. How old are you?

Jim 80 years old.

Jeff And when were you diagnosed with Parkinson's Disease (PD)?

Jim About 9 years ago in Dallas Texas.

Jeff What are you taking for medications?

Jim Stalevo with a supplement of Sinemet, 4 times a day.

Jeff There are many different symptoms of PD. What are your major symptoms?

Jim They come and go. The unpredictable nature of the symptoms is the one area where I can't get a grasp on things. I have no subtle warnings. Two years ago I had a pronounced shake in my right arm. It's almost not apparent anymore. I was just recently reexamined by the original Neurologist who diagnosed my case, the Professor of Neurology at South Western Medical in Dallas. Within the last three weeks, I was reexamined. Doctor ___ just scratched his head. He said "There's no rigidity. There's no shaking in your right arm except in anxiety situations". Also in anxiety situations, occasionally I have the inability to have my right foot to let go of the ground.

Jeff So you don't have PD.

Jim That's what they are wondering about.

Jeff You are still working, I understand.

Jim Oh yes. I'm a musician basically. I was a jazz musician as a young man. I played string bass and sang professionally for many years. I

recorded and played as a professional in big bands and small groups until we started a family. I need to go back farther than that. I started to play music when I was in an orphanage in Cleveland, Ohio where I was (if you will) incarcerated for 10 years. But at least they had music. My mother and father had been musicians. My mom was a concert pianist and my dad a successful band leader. And then Cancer and the Depression hit our family. My sister and I were orphaned and found our way to this home in Cleveland. I found my identity through music (which was really genetic), and I made a career out of music both as a player and later as a producer. I put my music away in 1961 and in 1994 returned to do an album titled Unfinished Business. I selected 11 songs and recorded them in 1994 when I was 70. The CD did well, and I found that it was the kind of music that appeals to People with PD (PWP). I had been diagnosed with PD and I joined a support group in Dallas.

Jeff What year would that have been?

Jim Maybe 1994. Soon after I was diagnosed. I had been Vice President and was ready to become President, when we moved to Connecticut about 3 years ago. I was the chief fundraiser for the group of about 1,000 people.

Jeff Did you find it hard to leave these folks and come up to Connecticut?

Jim I really did. We came up here at my daughter's behest to join her and her husband and my grandson and to be near my son who lives in Delaware.

So giving up the potential presidency of that wonderful group was a really emotional thing for me, as well as leaving Dallas after 40 years.

Jeff What major changes occurred with the move?

Jim I was not only a musician and a producer. I became a commercial voice-over person. I was the major voice in the Ross Perot presidential campaign in 1992 and 1996. I'm often billed as "America's Storyteller, Jim West".

Jeff I understand that you recently won an award.

Jim I won an Emmy for my work with Disney, children's stories from Malaysia, 13 animated stories called "The Ring of Fire".

Jeff Let's get back to PD. Your voice is your fortune. You make your living using your voice. Are you still playing instruments?

Jim No, I can't stand with a string bass anymore because of my balance. I really do have Parkinson's. My 200 year old string bass sits there (points to a corner of the room) longing to be played, but I'm afraid that I would fall and break it. Instead of that, I assembled a wonderful orchestra just this last year, 10 years after my other album, and at the age of 80 put out a new CD called Finished Business.

Jeff You have bookends.

Jim Yes. I aim to direct any of the profits from this CD toward PD, which is what I'm about.

Jeff Has your voice changed since you were diagnosed? Can you still do the voice overs?

Jim I can still do the voice overs. You find me today a little out of sync, only because I failed to do my exercises this morning. There's a program called LSVT, the Lee Silverman Voice Treatment. It's a treatment that encourages PWP (whose voice is going to soften, whether they like it or not), to maintain identity socially and within their family. With the LSVT you really can make a difference. The two basic words are THINK LOUD. You think you are shouting when you are speaking correctly.

Jeff We talked about not playing instruments any more. What else (if anything) has PD caused you to leave behind?

Jim I can't do the number of things I used to do. I was able to jump out of bed and when my feet hit the floor, I was off. Now I have to think about it. I have to make quality choices about what I'm going to do and apportion my time. That's a very

difficult thing to do. I still do a lot of pro bono work, everything from narrating an award winning breast cancer show to working for orphan children in foster homes in Russia and Rumania. My work is my hobby. I love to talk to small groups of PWP about LSVT.

Jeff What advice would you offer to a person recently diagnosed with PD.

Jim I think that they need a one-on-one consultation with someone with whom they can commune. Someone whose life story they can understand and who can subtly encourage them. The biggest thing is to help them to accept that which is inevitably going to come.

Jeff Did you join a support group?

Jim No, I've been visiting different groups, but my driving privileges were taken away. I was on Mirapex and fell asleep while driving, and my car tried to climb a fence! I've not been able to drive, and as a consequence getting to and from places has been difficult. Recently I hired a part-time driver so I'll be more able to get to places.

Jeff I feel very lucky to have a job that I could continue to do after I was diagnosed with PD.

Jim We're both very lucky. I have a new CD. I'm 80 years old and I defy anybody to tell me that I sound like an 80 year old man singing. So I'm continuing to do work that I can for people who need it. That's what I'm about. Recently I was diagnosed with Prostate Cancer. So what does one do? You get scared first. Then you decide whether to sit in a corner and suck your thumb or to stick your nose out there and forge ahead. In music you make everything that seems serious funny and we're able to accept whatever comes our way. So I told the Prostate Doctor who prescribed Female Hormones that I didn't want to wear high heels.

Jeff Just to close this out, I'd like to ask a tough question. What are your hopes for the future?

Jim I want to live as long as I can. I want to watch my children and their children grow because they are all we leave behind. The only footprints are those and in my older age, I realize they are not in stone, but are all in sand. But I'd like to see a cure. I hope for a cure; I pray for a cure. In my lifetime, it probably is not realistic, but it doesn't discourage me at all.

Jeff That's a good ending spot. Thank you for spending the time with me.

I was unable to get the Times' text; what I have is reference to it from another source. The story is what I was interested in, not source opinions, part of which is included. These two stories are frightening; I feel there are other such stories that we have not heard about. They make it absolutely clear that we need to educate as many people as possible to the needs of PWP, even (especially!) those in the medical community. —Stan

PD AND PRISON

The New York Times runs a piece on prison health care that exemplifies the best and the worst of the press. They collect a series of horror stories about Prison Health Services, a for-profit company that supplies health services to prisons in New York, among other places. Some of the stories are pretty awful.

Four days into his stay at the Schenectady County Jail, it all began to come apart for Brian Richard Tetrault. He could no longer walk the four steps from his bunk to the door of Cell 22, in A-block, where a nurse was waiting with his small ration of pills. Since his arrest, the state commission said, he had been denied most of the medication he had used for a decade to control his Parkinson's disease and psychological problems. The medical staff knew about his ailments from the day he arrived, soft-spoken and clutching a plastic pill organizer; they even phoned his doctor for his charts.

But the jail's medical director took him off all but two of his seven medications, and nurses concluded that the new inmate was more uncooperative than ill, state investigators said. Mr. Tetrault, a former nuclear scientist at the nearby Knolls Atomic Power Laboratory, had only seven days left before an agonizing death that investigators would label "physician induced."

What follows is the beginning of the story . . .

FIRST STORY

By 2001, [Parkinson's] had destroyed Mr. Tetrault's marriage and estranged his two teenage sons. His ex-wife, Eileen, had obtained an order of protection as he grew increasingly depressed and angry. That Nov. 10, he stormed into her home while she was away and snatched some items—skis and a push broom—before the police arrived and charged him with burglary and harassment.

His mistreatment began that day, according to the state commission. Without seeing Mr. Tetrault, the jail's medical director, Dr. W. J. Duke Dufresne, prescribed Sinemet and an anti-ulcer drug, but none of the other five medications for his Parkinson's, pain and psychiatric troubles.

On his second day in jail, Mr. Tetrault saw Dr. Dufresne, the only physician for the jail's 300 or so inmates. In a brief visit, the commission said, the doctor reduced even the Sinemet. As for the mental health drugs, Dr. Dufresne later told investigators that only a psychiatrist should prescribe them.

But no one ever arranged for Mr. Tetrault to

see the jail psychiatrist, the commission said. And never again did he see Dr. Dufresne, who told investigators he had believed that Mr. Tetrault was merely feeling the typical ups and downs of Parkinson's; he had planned to check on him in three months.

Mr. Tetrault had only days. On his fourth day in jail, medical records show, he grew increasingly "disky" and belligerent, as his body withdrew from the medications that had sustained him for years. On the sixth day, he lay in his bunk, steeped in his own urine and unable to move. "Continues to be manipulative," a nurse wrote.

On the seventh day, the commission said, nurses continued to look in on him, chronicle his deterioration and do little about it. "Inmate remains very stiff," one wrote. "Head arched back, sweating profusely," another noted. A third nurse forced him to walk to the jail clinic, though he could barely move.

On the eighth day, alerted by a nurse's phone call, Dr. Dufresne ordered Mr. Tetrault hospitalized. At Ellis Hospital in Schenectady, emergency-room doctors diagnosed the ravages of

(Continued on next page)

PD AND PRISON (continued)

his untreated Parkinson's. "I suspect, in the prison setting, he was not getting his full dose of medication as needed," wrote Dr. Richard B. Brooks.

There was not much the hospital could do. On the 10th day, Mr. Tetrault went into septic shock. On the 11th, he died.

The state commission ultimately referred Dr. Dufresne to the State Board for Professional Medical Conduct for what it alleged was "grossly inadequate" care, urged Prison Health to fire him and asked the county to fire Prison Health.

The commission found that Dr. Dufresne had never given Mr. Tetrault a physical examination; and nurses had transcribed the doctor's orders incorrectly, reducing even the Sinemet.

The problem is that we have no idea of what to compare these horror stories to. Is the prob-

lem that for-profit medical care is worse than government medical care, as the Times story suggests? The Times is singularly unhelpful.

SECOND STORY

One attorney explained what happened to one client, Gary Boylan, age 46, who suffers from Parkinson's disease. While driving he suffered a seizure, and asked a young girl to get help. She misunderstood him and thought that he wanted her to get in his car. The guards at the jail apparently thought that he was a child molester, and decided to give him a bit of their own kind of justice. On September 14 of last year they beat him to a pulp. He fell into a coma that lasted for four days, and had to be treated with hundreds of stitches to his head. Jail guards told Boylan's mother that he had a seizure in the jail and fell.

CPWG AFTER FIVE YEARS

Stan Wertheimer

I am writing this for several reasons: to help me decide where we are as a group; to start others thinking about the same question; to start to chart a course for the future; to shake up the membership. Since these are personal opinions I hope there are responses from those with differing views. If I receive written opinions I will include them in the newsletter. By the way, I get lots of verbal comments on the newsletter, but have yet to receive a written one; please take advantage of this forum and write a "letter to the editor" if you have a comment or opinion to be shared.

In a support group the members are mostly passive receivers of information and support. For most members the group provides an important component to their overall care and well-being. I think most of us gratefully acknowledge the good work support groups do. There is no easy definition of what a working group is, in our context. However, it is clear that members are interested in active participation. We also have a support component that is more broadly defined than that of a support group; we interact in a support context with many people each year who are not

members of our group, for example, we have a working component, where members can take part in support and education activities that are often a result of their own initiative. Thus, our working group must be considered differently from a standard support group. I hope this isn't too academic, another disease from which I suffer and was afflicted with in my early twenties. I thought it important to bring this distinction out.

Our reason for being is, as I see it, to provide support and education, where these terms are to be interpreted in the broadest sense. By support I mean not only that which we experience when we are in a place with others who share a chronic disease (the tradition perception of a support group) but also individual support that we feel when someone calls to see how we are, or comes to visit if we are restricted in our mobility as well as helping in the implementation of a web site or the publication of a newsletter. In this sense, Jeff Lincoln and Alyssa Morin are support people for me and I am support for Tom Sullivan when he runs a workshop. I like to think of support as a concept that brings people together to achieve a common goal—each member supporting the whole group. This doesn't happen as often as I would like to see it happen, probably because of human nature and,

in the case of PWP, because we are dealing with our own problems.

Where are we vis-à-vis support? I think we are in a good place; meetings surely supply an important support component, but in addition I have either experienced or heard of satellite gatherings around the state of people who met through CPWG. One place we could be stronger is in helping others who have taken the initiative in a project. Some examples: Skip Komisar has been asking for help in writing the copy for several of the web pages and has had no response; we wanted to distribute information packets to doctor's offices but there were few volunteers. I could give examples in the other direction as well, which is a lot more fun: Dan and Iola Yoder are self appointed mother figures, supplying refreshments for every meeting and not making a fuss about it; Jeff Lincoln volunteered to write interviews for the newsletter and has done a superb job; there are many other examples.

Now, where are we in the education realm? Our main ways to provide this component are, at present, the newsletter, speakers at meetings, outreach via the speaker's bureau (for us, not yet well defined), and personal contact. The newsletter seems to be in good shape (even if there was a duplicated article recently, which is embarrassing). Tom Sullivan and his (loosely constructed) team have brought some fine speakers and workshops to the group. Several members have spoken at gatherings of health care providers, newly diagnosed PWP, and other places where the audience was interested in PD—we could do a lot more of this. We tried having meetings around the state for newly diagnosed people, but that floundered and we have stopped. I suppose our new initiative (brainchild of Jackie) called MOTM (Meetings on the Move) is a form of educational outreach; this initiative has real promise.

There is another function our group provides, one that I didn't expect but probably should have: many of our members have become more involved and more active simply as a result of association with CPWG. Just by coming to meetings and talking with other members several people have been energized to get involved where the same person would not have been if it were not for the group. CPWG has provided a jumping off

place for some people who either were looking to be involved, or didn't realize they were looking until joining the group, where they found out they were. In this sense we are THE entity in the state that provides a home for the PWP who wants to join the battle in some way by being active.

Another place that I didn't anticipate we would be is as an actor in the PD landscape of Connecticut. We are a group different from others such as the APDA, PAN, NPF, and PDF. We interact with the research community (Institute for Neurodegenerative Disorders (IND), Hartford Hospital, UConn Medical Center, Dr. Murphy's group) differently from other groups. As such we have an as yet not well defined niche in the grand scheme. I imagine that niche will be better defined in the near future. By the way, some folks think we are affiliated with the APDA and/or IND; not so. We are completely independent, a decision Jackie and I made at the very beginning. We also are registered with the federal government as non-profit, and with the state as tax-exempt, thanks to the efforts of Jim Roy and Steve Holahan.

Where should we be going? I believe we should build from our strengths; that is, continue to build on those aspects of our current agenda that are working: support; education; outreach. I would like to see an initiative involving the creativity of our members, such as a craft catalog and/or a craft show. It would be great to have more members involved in speaking to the community, to both medical people and non-professionals. I still think getting information to doctor's offices is a good idea. MOTM seems to be taking off; perhaps we could expand on that idea. I think we can be a unifying force and bring together many of the PD groups working in the state which provide support and do research and at present do not interact. I see signs that we are about to get significantly larger; this both pleases and disturbs me. I would be glad to know we are of service to more people while at the same time concerned about losing the intimacy we now enjoy when gathered as a group. If we do grow, it will be a challenge balancing both aspects of growth.

I could sum up all of this; instead, why don't you write down where you think we are after five years? And discuss it with others.

CONNECTICUT PARKINSON'S WORKING GROUP



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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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