



Connecticut Parkinson's Working Group Newsletter

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This edition contains two Jeff Lincoln interviews and an article written jointly by Jackie Dorwin and Terry Deshefy-Longhi. One of the interviews is with me: it was Jeff's idea, it was edited by Debbie Weinstein, and I inserted it because it fit. I struggled with that one! It is good to see more participation perhaps in the future we might be sending out a newsletter dedicated to the musings of its members. We at the newsletter invite you to join us by contributing.

I would like to personally and publicly welcome Deb Weinstein as a new editor. She edited not only Jeff's interview with me but the Robot piece. I cannot tell you how liberating it is to have her help. She also has some exciting ideas for future articles: keep a lookout.....

JAMES R., CPWG TREASURER AND BOARD MEMBER EMERITUS

Jim was CPWG's first and founding treasurer. He put his business background to good use as one of the crucial players in CPWG as a Connecticut not-for-profit corporation. Jim was more than generous with his time and effort as he navigated CPWG through the paper work and bureaucracy of the IRS. The critical tax-exempt status, which CPWG has today, is in large part due to Jim's efforts back in 2002 and 2003. At the same time, Jim established a financial and accounting system, which is still in place today.

For all this know-how and dedicated hard work, which Jim put in to the early years of CPWG, a sincere thank you from the entire CPWG family. We would not be here as we are without you. Best wishes to Marie and you. Stay in touch!

— Steve Holahan

PAT G.—A SURPRISING LADY

Pat Gerace was a member of CPWG when it had no name. She tells the story of how she had given up hope of ever finding a support group that fit her idea of what a SG should be when, wonder of wonders, she stumbled upon us. She has been a faithful and dedicated member ever since, including being one of the original members of the board.

She has been adamant about always having time set aside for talk between members during a meeting, something we would forget from time-to-time, and always regret. However she was most impressive, and least known, for her absolute dedication to maintaining our mailing/membership list as it grew from a few tens to the over 300 it now contains. Without this list we would be lost: we need it to inform folks of meetings and send them their newsletters. It must be current and accurate. As it grew we found more uses for it. Pat was always there to help, and available to enter new names, often several a week. She cheerfully distributed it to the few people in CPWG who crucially needed to have it, yours truly included.

Now, here comes the mind-boggling part: Pat had never done anything like this on a computer and had very little or no background in data manipulation. She designed and implemented the list on her own with a diligence and dedication that are to be marveled at. We had a problem, Pat found a solution. I do not think many people were aware of the huge task this was, and how quietly and effectively Pat went about doing it.

This year she has decided to pass the baton on to someone else. She will always be a valued consultant to the new person as she assumes emeritus status. In her role as membership guru, board member and loving scold at meetings we have always valued her, and look forward to doing so many years in the future.

— Stan Wertheimer

ROBOTS

by Terry Deshefy-Longhi and Jackie Dorwin

What if you were given a robot, with no strings and no price tag attached to it? You know, one of those beeping, blinking, metal-looking, jointed machines on wheels that can be programmed to do certain tasks. It might help to picture the television show “The Jetsons”, with their maid robot, Rosey, or the movie “Star Wars”, with C3P0 and R2D2.

Technology is taking us down so many unimagined roads. One of them leads us to a college campus in New England where the development of a personal-care robot is being considered to assist chronically ill and disabled people. The question for you is this: What would you like programmed into the robot? You are probably still seeing dollar signs instead of benefits, but relax for a while and think about it If you could have a robot do some of the things that you can't do, or that you have difficulty doing, what would you want it to do? Don't be afraid that your choice seems trivial. One man's mountain/hurdle is another man's molehill/inconvenience. You get the picture.

At a recent CPWG meeting, this question was asked of the group and there were some interesting responses. Most of the group agreed that a ‘wife’ robot would be nice—to keep the place clean and tidy, do the laundry, go grocery shopping, chop onions and the like. Some CP's (care-partners) expressed concern about their own ability to lift and carry things, especially when their health or fitness was compromised. They thought the robot should be able to ‘fetch’. The robot (we've got to give this thing a name!) could wear a garment with lots of pockets for the cordless telephone, eye-glasses, meds, candies, etc. The robot could also be programmed to answer the doorbell and, in the process, transmit an image of the person at the door to the PWP. The ability to answer the telephone was also suggested, with special instructions for telemarketing calls.

As for taking care of the PWP, high on the list was a request for a med-dispensing capability. Not far behind was the ability to help the PWP if he or she should fall. That could get a bit tricky, but is something to consider. Other suggestions included assistance with dressing—laying out clothes for the day, holding up jackets for us to put our arms in the sleeves, and help with jewelry, such as necklace clasps and pierced earrings. And buttons! One person recommended that the robot be able to read to the PWP, since our eyes tire quickly and some of us struggle to hold the book and turn the pages. And who would not like help opening those blasted packages wrapped in all that plastic! One last suggestion had everyone nodding in agreement: to ask the robot to do things the PWP would not ask of the CP; a silly but perhaps clarifying example would be a case where the PWP has pet spiders and the CP has arachnophobia. Asking the robot to handle a spider would be the same as asking it to handle a glass of milk; not the same for the CP. This was something to think about.

So add your thoughts to ours. We'd like to hear from both PWP's and CP's and who knows—maybe a personal-care robot will be a reality before we can decide on its name.

INTERVIEW: STAN WERTHEIMER BY JEFF LINCOLN (6/13/07)

J: Let's start with a few items to establish the context. When were you diagnosed with PD?

SW: In 1990.

J: And how old were you?

SW: 55.

J: So that would make you 72 years old now?

SW: Well done.

J: What medicines do you take?

SW: Five. Sinemet (generic), Tasmar, Mirapex, Amantadine and Selegiline.

J: What medicine were you prescribed when you were first diagnosed?

SW: Sinemet.

J: Do I remember correctly that your mother had PD?

SW: Yes, she had it and she lived 35 years with the disease, without Sinemet, and in misery. To my surprise, I had no reaction when I was diagnosed with PD, even after watching her suffer for so long.

J: When you were diagnosed, were there any support groups?

SW: Yes, there was one in New Haven, and I found out about it from Donna Diaz. She asked me to come to a support group meeting. I went and brought my daughter. There were 8-10 of us wandering around like lost souls. The person who was supposed to lead the group had just told Donna that he couldn't do it any more, and Donna asked me if I would like to do it.

J: And so?

SW: I was still teaching, I was still doing pottery, and I was still raising kids. I didn't know if taking on the leadership of a support group was such a good idea, but I said "yes". We called the group "The Young Parkinson's Support Group". This group was for people recently diagnosed or those with early onset PD. Although most of the members were 35 to 45 years old, we had members as young as 15. There were only 8-10 of us, but that was my introduction to support groups.

Then I began working to get people involved. In two years we had 60 people. I started publishing a newsletter. I talked to a lot of people on the telephone. Donna referred newly diagnosed PWP to me for discussion. Often, these people would then come to the support group. The more people heard about it, the more they came to meetings. Everything was going

pretty smoothly. Our focus was not on speakers, but rather on communicating with one another. Then, in 1997, something happened in my life and I had to stop. Jackie Dorwin had begun to help me, but we both stopped and the group just petered out.

J: So then there was no support group?

SW: There were other support groups in Connecticut, but none like ours.

J: Obviously, there is a strong support group now. How did this come to pass?

SW: In 2000, I got a phone call from Jackie. She asked if I wanted to get started again. I said "Sure, let's do it". When we did start, once again we had about a dozen people. This time our name was the Connecticut Parkinson's Working Group or CPWG. I started publishing the newsletter again. This time, we were a little more organized. People began coming.

J: I noticed that the word "Young" disappeared from the name.

SW: "Working" took the place of it. The term "Working" did not mean "to be employed", but it meant "Functioning". We named ourselves what we are now. We seemed to fill a need and it just grew and grew and grew.

J: One thing that I think plays a crucial role in the success of CPWG is the newsletter. I wish that more people would get involved in supplying articles.

SW: I wish so too.

J: The other thing that is helpful is sending the reminder postcards. We announce every single meeting. This seems to be pretty important.

SW: Those are both instances of good communication, which is the key to success. Many people pick up a copy of the newsletter, they like what they see, and they call to get on the mailing list. It is surprising to me that we have 12 or 13 states represented in our list. Relatives often send the new PWP to us. The main reason we publish the newsletter is to keep people in touch with progress in PD treatment.

J: Do you come across many PWP who are trying to go it alone?

SW: Once in a while. What strikes me is that some of these people are pretty knowledgeable in general, but not with what they should know about PD. Often they are in denial, or they don't want to deal with it, or they feel it isn't so bad. They really should be keeping up with new developments.

J: I know. Jackie Dorwin also refers people to me who have been newly diagnosed. We talk. Do you do anything like that?

SW: I get 2-3 every month, referred by doctors, friends, other PWP, and Donna Diaz. We usually wind up talking for about 1/2 hour. I've been doing this for years. I hope it does some good. Most of these people are newly diagnosed.

J: Is there any common advice you would give to these folks?

SW: It is definitely a personal thing, but I know what I would do: seek out sources; read everything I could about it; make contact with other people; and immerse myself in the subject.

J: I told Dr. Jennings that I was in denial, even 1 year after she diagnosed me. Her answer was that denial was good. Anything that would get me through the day!

SW: The other thing I did was to get myself into clinical trials right away. But not everybody would want to do that.

J: One question that newly diagnosed PWP seem to struggle with, is deciding whom to tell or not to tell.

SW: I told my department (mathematics) at Connecticut College right away. I described the situation and got mixed reactions. The first question one of them asked was, "Are you still driving?" That was a show-stopper!

J: What changes in teaching did it require and what was the reaction of students?

SW: I didn't go around with a sign on my chest saying, "I've got Parkinson's", but I didn't deny it, either. I did do less work at the blackboard. During the last five years of my career, I gave no tests. The students loved it. They participated, wrote essays, and did experiments. They just didn't get tests or grades. I guess it worked well because students kept signing up for my courses.

J: Let's move on. After you retired, how did you decide what to do?

SW: After I retired, I was asked to participate in lots of things, but I decided to think about nothing but pottery, my family and the Connecticut Parkinson's Working Group [See sidebar -Ed.]

J: I, too, devote a fair amount of time to CPWG because I think it is worthwhile. You obviously keep busy, but sometimes do you find that you are too busy?

SW: Sometimes. I have asked for 2 editors to help. I can't do it all and you can't do it all. I think my job in CPWG is to keep the newsletter going and to think about where we should be heading as a group. I have no idea where we will be in five years, but I think we should continue in the current direction. Since we realize that we should not put undo pressure on anyone, we will never know exactly what our course will be nor how fast we will get there. The forum we organized in March was consistent with these goals and I was really pleased that it turned out so well. Everyone did a really fine job on that.

J: How do we ensure that CPWG continues into the future?

SW: That's a problem I've been thinking about. How do we find people to take over? And I don't know the answer. People think that because we (the J & S show) run the group, they do not need to take on extra work for themselves. They feel it has all been taken care of, but it has not! People have to step forward and offer to help. Eventually, these people may take over CPWG. Only if people get involved will we succeed.

J: So to wrap this up, CPWG is healthy and going strong, but is, paradoxically, always in need of more people to volunteer their help.

SW: People who give time to CPWG also take away a lot: the fun of involvement; getting to know great people; making a difference; and learning about the leading edge of PD research. There is no other support group in the state (or maybe the country) that does this any better than we do.

J: I think we'll leave it at that. Thank you for spending time with me.

Note from CPWG Member, Dave C.:

Dave was finding it difficult getting information about health insurance for a person with PD. So, when he found a web site containing a comprehensive brochure about health insurance in CT, he sent along the link to be included in the newsletter. Hope that this info is helpful to others in the group:

<http://www.healthinsuranceinfo.net/>

A PASSION FOR POTTERY

Stan Wertheimer with Jeff Lincoln

Jeff: In the main article, you mentioned pottery. Is this your hobby?

Stan: No! It's so much more. It's been a part of my life much longer than PD and is central to who I am.

Jeff: It sounds like pottery is your passion.

Stan: Yes, that would be a better way to describe it.

Jeff: Tell me how this came to pass.

Stan: I started in 1970. I was on sabbatical in England and my then wife said, "Why don't you take an evening course to break things up?" I said, "All right, I'll take pottery." I always wanted to know about it, which is what everybody says. But with me it was love at first sight. And I've been with it ever since. My ex-garage is my studio, complete with pottery wheels, a kiln and pottery pieces in various stages of creation. Also, right now I am participating in a show in Mystic. I have heard that there was concern that the pottery would all sell on the opening night. When a piece is sold, it stays with the show, but has a red dot so that people will know it has been sold. A typical good luck wish is, "May your show have the measles!" You can see every entry to the show, but you can't buy "Red Dot" pieces because somebody already has.

Jeff: How many pieces do you have in the show and how many sold?

Stan: About fifty pieces and about half sold in the four days that the show has been open. One thing that surprised me is that the most expensive pieces were sold first.



Jeff: It shows that your pieces have something that people are willing to pay for.

Stan: I only keep the pieces I like, and they may have some obvious features that most people would consider flaws. If I don't like the piece, I break it, and I end up breaking pieces deliberately at all stages of creation: raw clay, dried, bisque, glazing and firing. I see no reason to keep a piece that doesn't please me. I am glad that others seem to feel the same way.

Jeff: I have one of your "Test Tiles". It's beautiful and useless at the same time.

Stan: I use them as weights on the strings that hold up my tomato plants! Actually, I used them to learn the glazes for my pottery and, more importantly, to learn the interaction between glazes.

Jeff: I have a few of your pieces from an earlier show, and I'm very glad that you chose this particular passion. Also, I was pleased to help at one of your Raku firings. In a few minutes, dried and glazed pots were transformed into beautiful pieces by a marvelous process.

Stan: This year, I hope to build a bigger Kiln and do some larger pieces.

Jeff: I wish many successes and continued happiness with your passion.



PUTTIN' ON THE RITZ APOLLO SMILE-DAILEY (4/27/2007)

by Jeff Lincoln

Apollo Smile-Dailey is a choreographer, singer, dancer and teacher who lives in Guilford. A while back, she came to the VNA sponsored PD Exercise Group where she taught us several dance theater routines. I asked her to discuss ideas she has about dance. *Jeff*

J: We shall discuss the ideas you develop in your dance classes and how they relate to PD. Do you have it?

A: I don't, but my father does. He was diagnosed two years ago. He's 73 now.

J: Tell us a little about yourself, your background.

A: I grew up in Guilford and started dancing when I was three, doing gymnastics, tap and ballet. My mom got me involved in dance because when I was born, there was a tendon or ligament twisted in my hip; the doctor said that I might wind up in a brace from hips to ankles. Alternatively I could get involved in physical activity that would train me to have a turned-out hip. My mom immediately said "Let's get her into an exercise program". Today my chosen profession has to do with everything in dance theater.

J: You are a choreographer, an actress, a dancer and a teacher.

A: Yes to all of the above.

J: How does your work come in contact with PD?

A: My ideas for PD came from watching my parents dance. They liked to dance, and as I watched I realized that it is a great thing to be able to move freely. This made me want to teach older couples to move. Some seniors love to move, and remember back before they had things like PD or arthritis. So I talked about it to my father: "I've watched your exercise group, and I'd like to teach them movement through musical theater songs".

I thought, by making this choice, my approach wouldn't really be exercise as much as play acting. As I developed the program that I called "Puttin' on the Ritz", I would come home and show my father all the choreography that I had done and I would put the music on and perform for him. He would get so elated with watching, that I thought maybe I really could be able to do

something good and could bring this program to the PD exercise group. I was purposely theatrical about it bringing the hats, parasols and other props that my mother had collected over the years. Would this be fun?

J: Would you have to tailor that presentation for PWP's different from other senior groups?

A: I don't think so. Not drastically. The only things different that I recognized were positioning of the feet and balancing the steps. There may be some dance steps that seniors without PD might be able to do with greater ease. Quick direction changes for PWP's are not successful and may be scary. It's better if you can take more time to change direction, little steps instead one large turn. With PD, I specifically did not make choreography with too rapid changes.

J: So you have this interesting idea that music and motion can help PWP's. What are you going to do about it?

A: Working with the PD exercise class was a test, an experiment to see whether or not it would work. I think it proved successful.

J: People are still talking about it

A: Oh that's so great. I knew that I enjoyed it, but I was hoping everyone in the class would enjoy it. What I'm going to do is to offer the program that I call "Puttin' on the Ritz" probably through the Guilford Park and Recreation.

There's a new concept in "Puttin' on the Ritz", that I would like to develop called the "relief chair". This is basically a high backed office chair with arms and wheels. Some PWP's can't reposition and move to the music with balance. If they want to move and dance without worrying about balance, they can take a moment and sit in the relief chair and can then do the movements while in the chair. And the PWP can also spin around while completely balanced. So the chair gives the PWP a way to do something that they might not be able to do while standing. Finally, the relief chair allows someone to stand behind the chair and do partner dancing with the person in the chair or to walk around to the front and hold hands with the PWP while doing steps such a promenade or chorus line. I talked to the VNA about the chair and they said that this was a cool idea. The question is how could we afford to do this?

J: Chairs of the sort that you are describing are about \$50 so if you got five of them, that's quite a bit of money.

A: Yes, and with your group, I'd like to be able to provide four or five chairs. Just having the relief chair there is a relaxing concept. The class would aim to be 45 minutes long with 15 minutes of refreshments [Ritz Crackers? -Ed] and conversation. The whole idea is to be upbeat and not too tired at the last part of the class. My father has been an inspiration for me to develop concept choreography for PWP's. I'm learning new steps in this process too. As an instructor and teacher, that's rewarding to me.

J: I think that you would find that many seniors with many restrictions would be able to do more when following the music.

A: I could see this when we did "Hello Dolly". Everybody got involved enough to sing along with the music without my telling them to. Faces changed expression, and this doesn't always happen with PD. The PD mask fell away. The singing and the motion go together, and that's essentially musical theater.

J: I want to talk a little about the future and what might happen.

A: I will probably look to do this in the fall at the soonest. The Park and Recreation programs are already published for summer programs.

J: My last question. If you look ahead a couple of years, what do you see or what would you like to see?

A: Eventually, I'd like to have my own studio in Guilford. This would facilitate [presenting] a lot of ideas that I have already had as well as reaching out with the "Puttin' on the Ritz" to other senior's groups. I see the "Ritz" concept being fully developed and shared with other groups. I see a place where people like myself who love teaching, who love music, who love dance, who love acting, can have a place to develop new programs. There's no limit to what anybody can do. There's more here than exercise. The programs I would like to develop are not just for the body, but for the heart, for the soul.

J: We're going to stop on that note. Thank you for your time talking to me and especially for the time spent developing the "Puttin' on the Ritz" program.

PLEA FROM A MEMBER

Is there any PWP who suffers from the following symptoms

- At the end of the day as the Sinemet begins to wear "off" a tingling, burning, bee stinging sensation affects the bottom of my right foot;
- the right leg will also begin to painfully and uncontrollably hop and jerk around.

This occurs at the end of every day (no exceptions) and lasts for 2 1/2 hours until the leg and foot return to "normal" state of just being tired, weak, and wobbly.

I have consulted seven neurologists over the past 30 months with no satisfaction.

Please, please respond if you know of any possible solution to my problem.

Dick M.

Rmontross816 at aol.com

Please note 1 or more e-mail addresses of members have been edited to make them invisible to spam search engines by changing "@" to " at " in the address. To use the e-mail address, swap the " at " for "@".

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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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