

# Connecticut Parkinson's Working Group Newsletter

## *Special Edition* October 2003

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

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This special edition of the newsletter contains items that we felt needed immediate action, or items whose place is not usually in the newsletter. The item that takes up most of the edition is an index of the newsletters through August 2003. It was compiled by Dave C. He has volunteered to maintain this index as new issues of the newsletter are published. His willingness to do the initial job and provide maintenance is yet another example of a person willing to take on an important job simply because it needed to be done.

I have listed some other jobs that need to be done; they, as yet, have no one to do them. We hope people step forward, as Dave has done. There is also a short note on donations to CPWG and what we use our funds for. We depend on donations exclusively.

Several members have bought subscriptions for friends and relatives, as well as medical people in their lives. I explain what it means to subscribe and included a number to call, another example of a volunteer (Judy Iovanna) doing a necessary job.

Finally, I discuss Gunilla Norris's willingness to conduct meditation sessions before meetings for those interested.

### **Newsletter Subscriptions**

Our newsletter mailing list is now about 200. Included are members (those who participate by coming to meetings), other PWP, relatives and friends of members, selected doctors, medical people, support group leaders, and others who have requested that they be on our list. The newsletter is free to all but those that members have selected to send it to; they are subscription holders. Some reasons cited are: to let children know a little more about PD and how it affects their parents; to inform health care professionals associated with a PWP about PD; to inform friends about PD.

A subscription has been \$3 per year. Due to increased costs and more frequent editions subscriptions will be \$5 for the coming year, which just about covers our cost. Sending a subscription has the effect of informing someone, and usually more than one, due to passing the newsletter around. One of our chief aims is dissemination of information about PD. Hence, giving a subscription is very much in keeping with our reason for being. Consider it.

To enter a subscription contact: Judy I. at 203.237.4368

### **Meditation Before Meetings With Gunilla Norris**

Starting in November, Gunilla will conduct meditation groups at 9:15 a.m. on meeting days. Sessions will last 30 minutes. Everyone is welcome to attend. You are not expected to know anything about meditation, and you need not come to previous sessions to attend subsequent ones. Gunilla has been doing this professionally for decades; here is a chance to center yourself before a meeting with a well known practitioner at no cost.

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## **Your Dream Job Awaits !!**

**Stan Wertheimer**

Here is a list of some jobs that as yet have no one to do them. If you are interested contact the appropriate person, or Jackie or me . Many functions of the group are being covered by the membership; these people seem to enjoy what they are doing.

By participating you get a feeling of contributing to a great cause, meet up with some equally great folk, help advance the goals of CPWG and hence those of the greater PD community, and get a warm feeling from others who appreciate what you are doing. There is never any pressure from others - NEVER. If for some reason you have to slow down a bit, then do so, with the blessings and concern for your welfare by others in the group. It will be a positive experience if you choose to accept one of these *terrific* jobs.

**Construct a website** - this is not for everyone; if you have the expertise please consider it. Having a website is more than it appears on the surface. With a website we can send some people the newsletter electronically thereby saving about a dollar per copy; similarly for the newsletter index. We can make ourselves known to others outside (and even inside) the state with possible positive fiscal ramifications (grants, donations, ...). We can set up a place for people to leave messages for the group or a specific subgroup and have online conversations. It would be a starting place for your searches of the internet since we would have all the important links. This job has high priority.

**Contact local health care facilities to suggest discussing pd** - Jackie Dorwin and I have done this three times in recent months; it is a perfect use of our time and energy. The audiences have been enthusiastic; they tell us that they will be able to use what they have learned immediately in their work with PWP. Contact either one of us for more information about how you can do this in your locale.

**Deliver pd information to doctors' offices** - this has already been organized by Marge Krawczynski. I am listing a reminder that she needs people to actually get the job done. It should not take much time; if several of us do it, there will be a sizeable impact on newly diagnosed PWP in Connecticut. Contact Marge 860-793-8944

**Organize a pd film festival** - a long term project, but potentially lots of fun and a great way to spread information as well as a possible source of funding for the CPWG. The final result could go many ways; it could be a short experience or one spread out over several days. The emphasis could be historical, clinical, social, or a mixture of several approaches.

**Produce a report on pd-neurologists in ct/ri/ma/ny** - any newly diagnosed person would find this invaluable. How many of us are still with the person who first diagnosed us? It would also be a source for those who move, want another opinion, or are not happy with her/his MD.

**Produce a comprehensive report on research on pd in ct** - would involve speaking with those groups doing research in the state, such as IND, Dr. Murphy in Danbury and Dr. DeMarcaida in Hartford. One could also contact the pharmaceutical companies in the state.

**Survey the membership about interest in nutritional supplement buying club**

**Survey the membership for interest in buying drugs from canada**

**Survey the membership about carpooling to meetings**

**Investigate the plausibility of a cpwg crafts fair and crafts catalog** - many of the members are talented in craft work or one of the arts. A craft fair would be a great way of sharing the wealth and also an excellent fundraiser. A catalog could be distributed to those who might support our efforts thereby providing an outlet for the craft/art person, funding for CPWG, and a source of pleasure for those using the catalog. Contact me (860.572.9965), or Jim B. (860-274-8844).

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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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