

Connecticut Parkinson's Working Group Newsletter

Special Edition October 2003

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

Editor: Stan Wertheimer stan.wertheimeratgmail.com

Interview Editor: Jeff Lincoln

Distribution: Pam Lincoln, Pat G.

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.

Newsletter Index

Compiled by Dave C.

A

Acupuncture, alternative medicine, Jan '01 p2
Addictive behavior and Parkinson's, Aug '03 p1
Agonists, dopamine, initial treatment, Jul '01 p6
Agonists, dopamine, initial treatment, Mar '01 p8
Alcohol and Parkinson's, Aug '03 p1
Alpha-synuclein, Jul '02 p5
Alpha-synuclein, reaction with dopamine, Jul '02 p3
Alternative treatments, Oct '01 p3-5
Apomorphine, personal experience, Feb '03 p2
Automatic body functions, Apr '02 p1-3

B

Bee sting, beneficial effect, Oct '01 p5
Blood pressure, automatic body functions, Apr '02 p1-3
Blood test to detect Parkinson's, Jan '01 p10
Bone marrow, conversion to nerve cells, Oct '00 p8
Book review: Family Matters, Dec '02 p5
Book review: Helping Yourself Help Others: A Book for Caregivers, Jan '01 p6
Book review: Parkinson's Disease - 300 Tips for Making Life Easier, Feb '03 p8
Book review: Shaking Up Parkinson Disease: Fighting Like a Tiger, Thinking Like a Fox, Oct '01 p3
Book review: The Correstions, Dec '02 p5
Book review: When Parkinson's Strikes Early: Voices, Choices, Resources and Treatment, Jan '02 p8
Botulinum Toxin Type A for drooling, Aug '03 p2
Bowel movement, automatic body functions, Apr '02 p1-3
Brain stimulation, FDA warning, Feb '03 p9
Brain stimulation, medicare coverage, Feb '03 p12
Brain stimulation, personal experience, Feb '03 p4
Briggs, Roger, interview, Jan '02 p2-4
Briggs, Roger, interview, Oct '02 p1-5
BTX see Botulinum Toxin

C

Caffeine with Hormone Replacement therapy, Jun '03 p6
Caffeine, preventing Parkinson's, Jul '00 p7
Carbidopa + Levodopa + Entacapone - Stalevo, Aug '03 p2-3
Care giving, personal experience, Oct '00 p4-6
Care Web Pages, Jul '00 p6
CDS, Rotigotine patch, personal experience, Feb '03 p2
Chronic stress and Parkinson's, Aug '03 p4
Clinical research trials, benefits, Jan '01 p1
Clinical research trials, personal experience, Jul '00 p1
Clinical research, humor, Oct '00 p7
Clinical trials, Oct '00 p3
Clinical trials at Institute for Neurodegenerative Diseases, Jul '02 p6
Communication, CPWG, Jun '03 p6-7
COMT inhibitors (Comtan and Tasmar), Oct '00 p1
Comtan and Tasmar (COMT), Oct '00 p1
Congress and Parkinson's research funding, Feb '03 p13
Constipation, Jan '02 p7
Continuous delivery system, Rotigotine patch, personal experience, Feb '03 p2
Copper and Parkinson's, Aug '03 p3-4

CoQ10, Oct '02 p7
CPWG history, Jul '00 p3
CPWG history, Jul '02 p3
CPWG history, Oct '02 p13
CPWG information folder, Feb '03 p10
CPWG library, Jul '02 p3-4
CPWG mission statement, Jul '02 p2
CPWG workshop experience, Jul '02 p1
CPWG, information dissemination, Jun '03 p6-7
CPWG, name, Jun '03 p2
CPWG, Videos of meetings, Jun '03 p4

D

DaTSCAN, neuroimaging, Oct '00 p8
DBS see Deep brain stimulation
Deep brain stimulation, FDA warning, Feb '03 p9
Deep brain stimulation, Medicare coverage, Feb '03 p12
Deep brain stimulation, personal experience, Feb '03 p4
Deep brain stimulation, personal experience, Jun '03 p1-2
Deep brain stimulation, personal experience, Oct '02 p1-5
Dehydration, nutrition, Jun '03 p2-3
Diathermy, FDA warning, deep brain stimulation, Feb '03 p9
Digestion, automatic body functions, Apr '02 p1-3
Donations, medical equipment, Oct '02 p7
Dopamine agonists, initial treatment, Jul '01 p6
Dopamine agonists, initial treatment, Mar '01 p8
Dorwin, Jackie, interview, Oct '01 p1-2
Double blind, description, Jul '00 p1
Drooling reduction with by Botulinum Toxin Type A, Aug '03 p2
Drooling, automatic body functions, Apr '02 p1-3
Dyskinesia, induced by levodopa, Jul '00 p7
Dyskinesia, Viagra (sildenafil), Jul '00 p7

E

Early-onset Parkinson's, parkin gene mutations, Jul '00 p8
Eating guidelines, Jun '03 p2-3
Embryonic stem cell research see Stem cell research
Entacapone + Carbidopa + Levodopa - Stalevo, Aug '03 p2-3
Environmental agent research funding, Feb '03 p13
Environmental triggers, Oct '02 p9
Enzymes, effect on heavy metals, Aug '03 p3-4
Estrogen, Jan '01 p9-10
Estrogen with caffeine, Jun '03 p6
Exercise, personal experience, Oct '02 p8
Exercise, Yoga, Feb '03 p3

F

FDA warning, deep brain stimulation, Feb '03 p9
Fetal tissue research see Stem cell research
FlexAble, MSM with Glucosamine, Dec '02 p3-4
Flynn, Kevin, interview, Apr '02 p3-4
Folic acid deficiency, Jun '03 p3-4
Folic acid, vitamins, Oct '02 p7
Frenchay trials, Glial derived neurotrophic factor, Aug '03 p7
Funding, Parkinson's research, Feb '03 p13
Fungicides with Herbicides, Jun '03 p4-5

G

GDNF see Glial derived neurotrophic factor
Gifts, medical equipment, Oct '02 p7
Glial derived neurotrophic factor, Aug '03 p7

Glial derived neurotrophic factor, Jul '02 p4
Glial derived neurotrophic factor, Jun '03 p1
Glial derived neurotrophic factor, Oct '02 p10
Growth factor, Glial, Parkinson's treatment, Oct '02 p10

H

Hallucinations, sleep disturbances, Jul '02 p7
Heart disease, homocysteine, Jul '01 p6
Heart disease, linked to Levodopa, Feb '03 p8
Heart disease, Pergolide, Dec '02 p10
Heart nerve cells, related to Parkinson's, Oct '00 p8
Heavy metals and Parkinson's, Aug '03 p3-4
Herbicides with fungicides, Jun '03 p4-5
Homeopathy, alternative medicine, Jan '01 p2
Homocysteine, folic acid deficiency, Jun '03 p3-4
Homocysteine, heart disease risk factor, Jul '01 p6
Hormone replacement therapy and caffeine, Jun '03 p6
Hospitalization considerations, Jan '02 p7
HRT see Hormone replacement therapy
Humor, Jan '01 p2
Humor, for clinical research, Oct '00 p7
Hydrocarbon solvent exposure, Mar '01 p6
Hydrocarbon solvent exposure, Oct '00 p9

I

IL6 see Interlukin-6
Impotence, Apr '02 p1-3
IND see Institute for Neurodegenerative Diseases
Information dissemination, CPWG, Jun '03 p6-7
Institute for Neurodegenerative Diseases, Jul '01 p5
Institute for Neurodegenerative Diseases, Clinical trials, Jul '02 p6
Institute for Neurodegenerative Diseases, Research Vision award, Jun '03 p2
Interlukin-6 and Parkinson's, Aug '03 p4
Interview, Jackie Dorwin, Oct '01 p1-2
Interview, Kevin Flynn, Apr '02 p3-4
Interview, Roger Briggs, Jan '02 p2-4
Interview, Roger Briggs, Oct '02 p1-5
Iron and Parkinson's, Aug '03 p3-4
IRS Tax exemption, CPWG, Feb '03 p1

J

Jokes, Dec '02 p9

K

Keyboard therapy for Parkinsonians, Oct '00 p6

L

L_Dopa, slowing Parkinson's progression, Feb '03 p12
Levodopa + Entacapone + Carbidopa - Stalevo, Aug '03 p2-3
Levodopa, induced dyskinesia, Jul '00 p7
Levodopa, linked to heart disease, Feb '03 p9
Library, CPWG, Jul '02 p3-4
Lipitor, related to Parkinson's, Jul '02 p6

M

Maneb fungicide with Paraquat herbicide, Jun '03 p4-5
Manganese and Parkinson's, Aug '03 p3-4
Massage therapy, alternative medicine, Jan '01 p2
Medical equipment donations, Oct '02 p7
Medicare coverage, deep brain stimulation, Feb '03 p12
Medication meeting video, Jun '03 p4
Meditation/Tai Chai before CPWG meetings, Jun '03 p7

Meeting videos, Jun '03 p4
Methylsulfonylmethane, Oct '01 p6
Methylsulfonylmethane, personal experience, Dec '02 p3-4
Mevacor, related to Parkinson's, Jul '02 p6
Mirapex, related to sleep disturbances, Jul '02 p7
Mission statement, CPWG, Jul '02 p2
Movers and Shakers of New England, Jul '00 p2
MSM see Methylsulfonylmethane

N

Naturopathy, alternative medicine, Jan '01 p2
NeoTherapeutics Inc., netrofin, Oct '02 p11
Nerve Growth Factor, Aug '03 p7
Netrofin, Oct '02 p11
NETRP funding, Feb '03 p13
Neuroimaging, Oct '00 p3
Neuroimaging, clinical research trials, Jan '01 p1
Neuroimaging, DaTSCAN, Oct '00 p8
Neuron death, Jul '02 p5
Neurotoxin Exposure Treatment Research Program, Feb '03 p13
Newly diagnosed, personal experience, Jul '00 p4
Newsletter subscriptions, Feb '03 p11
NIH funding for Parkinson's research, Feb '03 p13
Novartis, Stalevo, Aug '03 p2-3
Nutrition, excess Iron, Aug '03 p4
Nutrition, guest speaker, Feb '03 p11
Nutrition, meeting video, Jun '03 p4
Nutritional guidelines, Jun '03 p2-3

O

Occupational risk, solvent exposure, Mar '01 p6

P

Pallidotomy, Jul '00 p7
Pallidotomy, personal experience, Feb '03 p4-6
Paraquat herbicide with fungicide Maneb, Jun '03 p4-5
Parkin gene mutations, Jul '00 p8
Parkinson's 'personality' predisposition, Aug '03 p1
Parkinson's Study Group, Oct '00 p1
Patch, Rotigotine CDS, personal experience, Feb '03 p2
PD see Parkinson's disease
Pergolide, valvular heart disease, Dec '02 p10
Perlman, violin article, Jul '01 p2
Permax, related to sleep disturbances, Jul '02 p7
Personality traits, Parkinsonians, Jan '02 p4-6
Pesticide exposure, Jul '00 p7
Pesticide exposure, Jun '03 p4-5
Pesticide study, Jan '01 p9
Pesticides, Mar '01 p7
Phase I, II, III clinical trials, description, Jul '00 p1
Phone tree, Feb '03 p10
Piano playing with Parkinson's, Oct '00 p6
Pig embryonic cell transplant, Jul '00 p6
Placebo effect, Feb '03 p7
Placebo effect, Oct '02 p5
Pramipexole, inhibiting cell death, Jul '01 p8
Pravachol, related to Parkinson's, Jul '02 p6
PSG, Oct '00 p1

Q

Q-10, vitamins, Oct '02 p7

R

REM, sleep disturbances, Jul '02 p7
Remacemide, Jul '00 p6
Requip, related to sleep disturbances, Jul '02 p7
Research funding, Feb '03 p13
Research Vision award from Institute for Neurodegenerative Diseases, Jun '03 p2
Research Walk, Institute for Neurodegenerative Diseases, Aug '03 p1-2
Rotenone, pesticide, Jan '01 p9

S

Salivation, automatic body functions, Apr '02 p1-3
Salivation, automatic body functions, Aug '03 p2
Selegiline, death rate, Mar '01 p7
Sex, Men vs Women with Parkinson's, Jan '01 p9-10
Sexual activity, Apr '02 p1-3
Shallow water exercise for Parkinson's, Aug '03 p5
Sildenafil, effect on dyskinesia, Jul '00 p7
Sinemet and eating, Jun '03 p2-3
Sinemet, slowing Parkinson's progression, Feb '03 p12
Sleep disturbances in Parkinson's, Jul '02 p7
Smell, inability of Parkinsonians, Jul '01 p7
SOD see superoxide dismutase
Solvent exposure, Mar '01 p6
Solvent exposure, Oct '00 p9
SPECT imaging, clinical research trials, Jan '01 p1
SPECT imaging, Oct '00 p3
Stalevo, FDA approval, Aug '03 p2-3
Statins, related to Parkinson's, Jul '02 p6
Stem cell research, Jan '01 p10
Stem cell research, Jul '00 p6
Stem cell research, Jul '01 p6
Stem cell research, Oct '00 p3
Stem cell research, Oct '02 p12
Stem cell research funding, Feb '03 p13
Stem cell research, religion, Oct '00 p8
Stem cell transplantation, lack of benefit, Dec '02 p1-2
Stress and Parkinson's, Aug '03 p4
Subscription, newsletter, Feb '03 p11
Subthalamic nucleus stimulation implants, Jul '00 p7
Superoxide dismutase and Parkinson's, Aug '03 p3-4
Support group, benefits, Jul '01 p3
Swallowing, automatic body functions, Apr '02 p1-3
Sweating, automatic body functions, Apr '02 p1-3
Tai Chai/meditation before CPWG meetings, Jun '03 p7

T

Tax exemption, CPWG, Feb '03 p1
TCH346, Jan '01 p11
TCH346, Jul '00 p5
TCH346, Mar '01 p6
Telephone tree, Feb '03 p10

U

University of Kentucky, Jul '02 p4
Urination, automatic body functions, Apr '02 p1-3

V

Valvular heart disease, Pergolide, Dec '02 p10
Viagra, dyskinesia, Jul '00 p7
Viagra, sexual function, Jul '00 p7
Videos of CPWG meetings, Jun '03 p4

Vitaline, vitamins, Oct '02 p7
Vitamins, Oct '02 p7
Vitamins, folic acid, Jun '03 p3-4
Vitamins, nutrition, Jun '03 p2-3

W

Walk, Research, Institute for Neurodegenerative Diseases, Aug '03 p1-2
Water exercise for Parkinson's, Aug '03 p5

Y

Yale Movement Disorders Center, Oct '00 p3
Yoga, alternative medicine, Jan '01 p2
Yoga, personal experience, Feb '03 p3

Z

Zinc and Parkinson's, Aug '03 p3-4

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).

Connecticut Parkinson's Working Group
132 Highwoods Drive
Guilford CT 06437

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

WRITE! your representatives in congress.

Christopher Dodd
Russell Senate Office Building
Washington, D.C. 20510

Joseph Lieberman
Hart Senate Office Building
Washington, D.C. 20510