CONNECTICUT PARKINSON'S WORKING GROUP Newsletter June 2005

Recent donors have contributed approximately $1000 since the last newsletter.
In addition to the these CPWG received an unrestricted grant of $2000 from Schwartz Pharma.

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
Glastonbury, CT 06033-3009

==========

Summer Events

CPWG SPONSORS GOLF OUTING

A non-competitive golf outing for PWP's and friends will be held at Portland West Golf Club, Route 17, on Wednesday August 3rd, beginning at 1:00 pm. The 9-hole event costs $25.00 and includes golf, cart and prizes. Refreshments are available for purchase. Non-golfers are welcome at no cost. All golfers must pre-register. Call any of the following for information: Jeff Lincoln 203-453-3383, Jackie Dorwin 203-453-2655 or Tom Sullivan 860-526-5021.

The following three events will also take place this summer. Enjoy them and golf.

Pat Gerace and Jackie Dorwin host a day of companionship at the beach.
Date: August 15th at 11:00 a.m. - 3 p.m. Place: 28 Waterbury Road, Madison
Bring: Beach chairs and Food: Main dish for yourselves such as hamburger or hot dog to cook on the grill. and a side dish to share with the group such as a salad, fresh fruit, vegetables, or a dessert. Cold drinks will be provided.
Please respond by August 8th if you are planning to come.
Directions to Waterbury Road will be available.
Numbers to call:
Pat 203-269-0348 Jackie 203-453-2655

Keep August 6 open for the CPWG Partners Appreciation Day

You're all invited to express your appreciation to the people who do so much for us and are some times taken for granted. On August 6th we will show our appreciation during a picnic/potluck/ cookout at a park to be determined.
Details to follow. Keep this date open. Guido S. guido@rh.edu
Tel: (860)633-1026 105 Martin Terrace, Glastonbury, CT 06033

K. Picnic on July 16 at Noon

For directions and more information call Skip at 203.699.9075 . They live at 35 Kristen Court in Cheshire and have an unusual garden. They had a picnic last year and it was a great success.

To the Editor: CPWG newsletter

I am writing to CPWG newsletter with the hope and intention of developing another avenue for exchange of ideas among the readers of this newsletter. After having numerous discussions about a myriad of topics, it seems our members frequently are an excellent source of information. What I would offer as a topic today involves the introduction of stress, anxiety or even sheer excitement as a trigger to intensified display of PD symptoms. I know in my case, my symptoms become exaggerated when I am anxious or excited. My attempts to maintain an emotional equilibrium are frequently thwarted by challenges of everyday life. My own solutions center on participating in some form physical activity, usually outdoors, weather permitting. This seems to re-center my perspective and reduce my symptomatic activity. I would be interested in hearing about other perspectives. Share your ideas through this newsletter. Thanks. **Tom Sullivan**

Incidence of PD: Variation by Age, Gender, and Race/Ethnicity

Stephen K. Van Den Eeden1 et al.

ABSTRACT: The goal of this study was to estimate the incidence of PD by age, gender, and ethnicity. Newly diagnosed PD cases in 1994–1995 were identified among members of the Kaiser Permanente Medical Care Program of Northern California, a large health maintenance organization. Each case met modified standardized criteria/Hughes diagnostic criteria as applied by a movement disorder specialist. Incidence rates per 100,000 person-years were calculated using the Kaiser Permanente membership information as the denominator and adjusted for age and/or gender using the direct method of standardization. A total of 588 newly diagnosed (incident) cases of PD were identified, which gave an overall annualized age- and gender-adjusted incidence rate of 13.4 per 100,000 (95% confidence interval (CI): 11.4, 15.5)[see note]. The incidence rapidly increased over the age of 60 years, with only 4% of the cases being under the age of 50 years. The rate for men (19.0 per 100,000, 95% CI: 16.1, 21.8) was 91% higher than that for women (9.9 per 100,000, 95% CI: 7.6, 12.2). The age- and gender-adjusted rate per 100,000 was highest among Hispanics (16.6, 95% CI: 12.0, 21.3), followed by non-Hispanic Whites (13.6, 95% CI: 11.5, 15.7), Asians (11.3, 95% CI: 7.2, 15.3), and Blacks (10.2, 95% CI: 6.4, 14.0). These data suggest that the incidence of PD varies by race/ethnicity.

Note: A 95% confidence interval (CI): 11.4, 15.5 means that the probability of the ACTUAL rate being between 11.4 and 15.5 is 0.95. The best guess is 13.4.

Taken from the Am J Epidemiol 2003; 157:1015-1022

Taking Your Medicine

Stan Wertheimer

It sounds simple – you have medication as pills and all you have to do is take it to feel better. As many PWP have discovered, it aint so easy! When taking Sinemet (the generic form is

carbidopa/l-dopa), for example, it can be crucial how you take it, when you take it, what you have eaten before you take it, what you will eat after you take it, what you have eaten with it, how long since you ate and will eat again, what duration of time you have been taking it, and your physical orientation, to name a few criteria. I'll try to address these points from my very personal point of view – others may have different stories to tell.

How? I use water or tea, with the occasional seltzer thrown in. I break the pill into several pieces with my teeth. Chewing has been suggested for quicker absorption in the small intestine, where it must go before doing any good at all. I have also heard of people using milk, which is playing with fire, as the protein in the milk might fight it out with the l-dopa once it gets to the small bowel, since l-dopa is a protein and there are just so many protein receptors. I also try to drink at least one whole glass of liquid, again, to get things moving through the stomach. The more time spent in the stomach, the more l-dopa gets metabolized, the less that is available for the brain to convert to DA. Note: there is a drug available from Canada (not in the USA), domperidone, which hastens movement through the stomach. I understand that it works.

When? If you have a full stomach when you take your meds, they get diluted and become harder to absorb quickly; also, they spend more time doing no good in your stomach. So I take Sinemet, or carbidopa/l-dopa, on an empty stomach (which for me means two hours after I have eaten). For the same reason I wait an hour after I have taken l-dopa to eat.

What eaten? Sometimes I wonder if one needs a PhD in chemistry and biology to successfully medicate PD. It turns out that if you eat lots of proteins near to taking a dose of l-dopa (also a protein) the effect of the dose is attenuated and can be negated. The reason has to do with absorption of the proteins in the small intestine – if there are more each one gets less attention – sort of like having kids.

What you will eat? This seems to be less crucial to me; I try to keep away from heavy concentrations of protein after a dose of l-dopa; it is still being absorbed when digestion is slow.

What eat with? The advice I have always gotten is: take your l-dopa on an empty stomach. However, there is the question of swallowing. If I feel that one of my pills has hung up in my esophagus I will take a few bites of the driest cracker I can find, which helps me to swallow the offending pill.

Duration? I have been told that the longer one takes Sinemet the less effective it becomes, where the time may be measured in many years. This means that even though not much has changed with you, the same dose of Sinemet may not produce the desired result in symptom alleviation.

Orientation? I have not investigated this one, but it seems that if one is lying down medication will move through the system at a different rate than if one is walking, or just standing.

So, just taking your medicine can seriously short change your response, depending on many factors, some of which seem completely unrelated to taking the medication. Know what you are taking, how you should be taking it, and what the expected results are.

Data Link Insecticide And Parkinson's

Researchers report the discovery of a possible link between a common insecticide and the development of Parkinson's disease (PD). "We have found fairly low-dose effects of permethrin, an insecticide used by the military and on food crops" on a brain protein and DA uptake levels, reported Jeffrey Bloomquist, a professor of toxicology and pharmacology at Virginia Polytechnic Institute in Blacksburg. "These changes could lead to PD," he told UPI.

Bloomquist and his colleague Bradley Klein, professor of neurobiology at the Virginia-Maryland Regional College of Veterinary Medicine, also in Blacksburg, presented results of

their U.S. Army-funded research at the annual meeting of the American Chemical Society. They found low levels of the insecticide -- commonly used to protect cotton, corn and other crops from insect devastation -- were related to lower DA production. A decrease in this neurotransmitter's production in the brain has been linked in earlier research to the loss of motor skills associated with PD.

In addition, permethrin, also used to "impregnate (troops') uniforms to repel insects," affected levels of the protein alpha-synuclein, Bloomquist said. His research suggested too much of this protein could cause formation of Lewy bodies -- fibrous clumps seen in the brains of PD patients.

Though changes in the brain's neural pathways caused by permethrin exposure could lead to PD, Bloomquist said the research has not established a conclusive link. The changes are consistent with a pre-PD condition, but not the full-blown disease, he explained, adding genetics also plays a probable role in a person's susceptibility to PD.

The U.S. Army, which funded the initial research, has indicated support for additional studies, Bloomquist said. "We want to look at longer exposure to see if we get something that looks like full-blown PD," he added. The results presented at the ACS meeting were based on injections administered over short, two-week periods. [I must assume that their subjects were denizens of the animal kingdom – perhaps mice or rats. Stan]

The research fits into a larger category of association between insecticides and PD. One clue to the link is the elevated risk for the disease in areas where insecticides are commonly used. "There has been similar work done," said Dr. Charles Adler, professor of neurology at the Mayo Clinic in Scottsdale, Ariz. "The epidemiological data suggest people in rural areas have higher rates of PD."

Bloomquist's results could help confirm other evidence that insecticides can contribute to PD, Adler said.

This is printed from:
http://www.applesforhealth.com/HealthySenior/datinspark4.html

{It should be pointed out that both Dr Tabamo and Jeff were the panelists for that day; Jeff was there to field questions best answered by a PWP. Stan}

Dr. Rowena Tabamo & Jeff Lincoln, PWP : The Gables, Farmington

Your Interview Editor is taking some time off over the Summer. Instead of an insightful and timely interview, I have for you an insightful and timely question and answer session which took place at the Gables in Farmington last February. Dr. Rowena Tabamo from the Institute for Neurodegenerative Disorders (IND) took questions from a large audience. Here's how it went.

Question: A lot of people think that Parkinson's Disease (PD) is caused by dopamine (DA) neurons degenerating in the brain. I've always felt that that's a symptom of PD. Could you straighten that out for us?

Dr. T: From what we know of the disease process of PD, this is what happens. The cells in that part of the brain that produce a chemical called DA are actually dying. Their absence leads to tremor, slowness of movement, walking problems, and rigidity. But we don't know what causes the cells to die. There may be genetic and environmental factors.

Q: If you could somehow keep the cells from dying, you still wouldn't have cured PD?
Dr. T: If you could somehow keep the cells from dying, that would be basically curing PD. There are different theories as to why the cells die. Thus, if you had strokes in this part of the brain, that's an insult to the brain and could be involved in PD.
Q: I had two different diagnoses by two different doctors, one of PD and the other of Parkinsonism. Which should I believe?
Dr. T: It's not as easy to diagnose at the early stages because the symptoms reveal themselves over time. So it's not easy for a neurologist. That's why it's important to develop further objective measures of how to diagnose PD.
Q: The problem I have is that I don't sleep well at night. Is that a common thing?
Dr. T: It's one of the things we see in patients with PD. Symptoms may bother you at night. Perhaps you have to go the bathroom several times a night. The short answer is that it is important to sort out why you have sleeping problems because there are many things other than PD that can cause sleeping problems. Maybe it would be best for you to go back to your neurologist and let him know that you are having side effects from your PD medications. He might want to give you a different medicine.
Q: I participated in the imaging studies that you conduct down in New Haven (Institute of Neurodegenerative Disorders – IND). Is that research still going on, and what have you learned from that?
Dr. T: We're still doing research on imaging. It's not yet FDA approved. What we are trying to develop a useful diagnostic tool which can look into the progression of PD. What we do is to inject a radio-tracer into the patient. It attaches itself to the DA cells. Looking at these markers allows us to visualize the amount of DA neurons in this part of the brain. We can then compare PD subjects to normal subjects to see how much cell loss you would expect. There are a lot of drugs being studied to see if they prevent the loss of the cells. And it's good to have an objective measure.
Q: Is there a genetic link to PD?
Dr. T: There are families that have PD. This allows us to study the genetic abnormalities. There are some gene abnormalities that are related to PD. The problem is that some people with PD don't have these gene abnormality especially if they develop PD later in life. So it's hard to say PD is all genetic or all environmental. Probably it's a combination of factors.
Q: How does a person get involved with clinical studies?
Dr. T: At IND, It depends on the drug study. It's something where they have strict inclusion- exclusion criteria. Then again, there are different clinical trials at IND in different stages of the disease. It could be [that the researchers are looking] for people newly diagnosed or that have had no motor fluctuations. Sometimes we are looking for health people to act as controls.
Q: We were lead to believe that anti-depressant medicine would interfere with Comptan and Levodopa. Can you give us some encouraging news that they don't?
Dr. T: We have many patients who are taking anti-depressants with other PD medicines. So it's a matter of figuring out the right anti-depressant for you. Depression is one of key symptoms in PD and has to be addressed. Many PD patients are on anti-depressants and don't seem to have a problem with other PD drugs.

Q: Doctor, I seem to have a problem reading. When I'm reading, I get very sleepy. Is that a common problem for people with Parkinson's Disease (PWP"s)?
Dr. T: Sleepiness can be a problem, but the question is can the drugs cause this? Many PWP's have difficulty sleeping at night.
Q: Can you give us your opinion on Vioxx?
Dr. T: It's one of the Cox2 inhibitors. There's a lot of controversy in the press now because of the risk for cardiac illnesses. The interesting thing about it right now is the belief about inflammation and PD. Could the increased inflammation actually triggers cell death? There are going to be studies done to look into Cox2 inhibitors. However, we will have to make sure it's given to the right group of patients because of the higher cardiac risk.
Q: I've had PD for 13 years and lately when I get up in the morning I freeze and I have to have a lot oaf help walking. Are my symptoms increasing or is it the medication?
Dr. T: It could be a symptom of PD or it could be a symptom of the medication. Do you freeze before or after your first dose of medicine? What you might do is to move your first dose of medicine up. At that time it is the longest you have gone without medication. When the medicine kicks in, hopefully you will have less freezing.
Q: Would you comment on Deep Brain Stimulation (DBS)?
Dr. T: It's a good treatment. It's actually putting electrodes in a certain part of the brain to try to control symptoms. It is a surgical procedure. There are some risks to it, but it is one of the tools we use for PD. It seems to be most effective in treating tremor in patients where medication no longer is effective.
Q: What are the risk factors for developing PD?
Dr. T: Age, family history, exposure to certain chemicals in the environment, but often it's hard to figure out what causes PD. Most PD is labeled "Ideopathic" which means that we don't know what caused it.
Q: I've heard that with Sinemet you build up a tolerance. Is this also true of Requip?
Dr. T: We believe from experience that if you start out with a DA agonist, the onset of these long term complications will be delayed. Most people do start with a DA agonist first. The onset of long term complications seems to be pushed back. But on the other hand, some people don't tolerate Mirapex so we give them Sinemet. We have to give them what works.
Q: Is Distonia related to PD?
Dr. T: It is a completely different problem. Dystonia is another kind of symptom where you have muscles acting together at the same time so that you maintain a certain posture. Sometimes people have their neck tilted to one side or their hand is twisted in a not normal posture. It's interesting because people it can be another separate problem or occur together with PD. People can have Dystonia and not have PD. If people do have PD and Dystonia, usually they have had early onset PD and often the Dystonia occurs in the early morning hours. It may be related to an "off" period, when you haven't taken medicines for a while

So that's how the Q & A session went. If this type of activity interests you, plan to visit a meeting of the Connecticut Parkinson's Working Group. We get into this type of

discussion often and explore many facets of PD. Most of all, we enjoy each other's company and support.

Jeff Lincoln

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

Joseph Lieberman

Russell Senate Office Building
Washington, D.C. 20510

Hart Senate Office Building
Washington, D.C. 20510