Connecticut Parkinson's Working Group Newsletter

June 2003

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Editor: Stan Wertheimer stan.wertheimeratgmail.com
Interview Editor: Jeff Lincoln **Distribution: Pam Lincoln, Pat G.**

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This newsletter has some interesting articles about how to deal with your medication and some research which sounds promising for the near future. There is an uplifting article by Steve Holahan and a notification by Jackie Dorwin of recognition of the groups efforts to spread the word by IND. You will also find a discussion of how we diffuse information. Oh yes, there are pieces on the effect of hormones, folic acid, and caffeine on the brein.

Next time we shall hear more about an index of this newsletter already compiled by David Curtin and, I hope, some personal theories by new and old (the French have a way of dealing with the ambiguity here - I mean long time) members.

Triple hope for PD

Brain catheter feeds beleaguered cells; taking iron out protects them.

A drip-feed of protein through the skull has transformed the lives of five PD patients, say scientists. Doctors implanted a thin plastic tube into the patients' brains and a small pump in their stomach. They infused a molecule known to nourish the brain cells that wither during PD: glial-cell-line-derived neurotrophic factor (GDNF).

After two years of treatment, "we're seeing improvements across the board", says team leader Steven Gill of the Institute of Neurosciences in Bristol, UK. One patient, whose movement problems left him housebound, has joined his local bowls team; another re-wired his house.

Gill claims that this is the first time a treatment for PD has reversed - rather than simply stalled - disease progression. The rejuvenated brain cells began to sprout and produced more of the chemical dopamine, which is essential for normal movement. With another five years of trials, this could become a routine treatment, says Gill: "I think people should be leaping up and down."

PD researcher Warren Olanow of Mount Sinai School of Medicine in New York is more sceptical. "Theoretically it's very nice," he says - but a long-term infusion might cause unknown side-effects. A trial of fetal brain-cell transplants, for example, caused controversy in 2001 when some patients developed uncontrollable movements. "You have to take [the results] with an enormous grain of salt," warns Olanow.

HELEN PEARSON 31 March 2003

IT WORKS!!!

Date: Mon, 3 Mar 2003
From: Steve Holahan <stevebycatcox.net>
To: Stan Wertheimer < stan.wertheimeratgmail.com >

While PD will remain with me, I can say this chapter is about to close with a victory for the good guys. Last Thursday up in Boston, they turned on the two stimulators (Pacemakers) and after some back and forth on each side, initial settings were made and a revised drug schedule adopted to go with it. Results as of today, late Monday, I have not had one "OFF" since the things were turned on. My left side tremor which was getting lots worse, is almost completely gone. And no leg freeze-ups and no falls! Still feel a little

lethargic, but getting better each day. And sleep comes in 4-6 hr chunks, not the 1-3 hrs before. I will go back to Boston every couple of weeks for follow up and tweaking the settings, and going to lower drug doses.

Needless to say I'm thrilled at the results, and also very humbled at the amount of human energy and resources that went into this procedure. From the skill of the surgeon, to the friendly smiles and professional care of the nursing staff, to the thorough top notch professionalism of the Movement Disorder Group, I owe the people of Beth Israel Deaconess Medical Center a deep and profound "Thank You"; I just hope that as many of my fellow PDers as possible can avail themselves of this therapy.

I want to thank you all, this mish-mash of family and friends who have been such a positive force, and this kind of force is real, as is the incredible power of prayer. There were so many little jump starts that I got. Emails, phone calls, conversations, and cards, and the food that our Glastonbury friends provided. From the bottom of my heart (if not my SubThalamic Nucleus) I thank you one and all for this huge massed and focused positive energy.

Bernadette, who certainly has her own cross to bear, was there beside me every step of the way. She dealt with the unedited version of the noble Parkinsonian. She has been a companion, friend, cheerleader and driver par excellance. And she was just always there even when her own illness was causing her unspeakable pain. I just pray she'll get the same kind of medical breakthrough!!

Thankfully yours, Steve

IND Research Vision Award

Date: Mon, 26 May 2003 15:00:51 EDT
From: JDORWINataol.com
To: stan.wertheimeratgmail.com

A while ago there was some discussion about the name of our group, especially the use of the word "working." Some interpreted it as "employed; receiving a paycheck." Others thought it meant "being active." Still others could define it either way, thought it confusing, and wanted to eliminate it. Round and round we went until it was decided that "working" stayed and it means "being active." If people misunderstood it, they would be corrected when they experienced our group in action.

So here we are, the Connecticut Parkinson's Working Group. Our name does reflect the group's intentions accurately. We have been and continue to be passionate about helping the Parkinson's community in Connecticut, and our activities have not gone unnoticed. In May the Institute for Neurodegenerative Disorders presented the Second Annual "Research Vision Award" to the Board of Directors of CPWG. In giving us this award, IND acknowledges our "efforts in furthering the dissemination of knowledge to those affected by Parkinson's disease in Connecticut."

This award is an affirmation of our work already done, and with a hopeful look to our future. With research, more effective treatments and a possible cure for this disease are coming tantalizingly closer. With knowledge, the quality of life for people affected by Parkinson's is enhanced. We are truly honored by this recognition, and we are committed to a future of continued collaborative efforts for the benefit of the Parkinson's community in Connecticut.

NB: Jackie is on the IND board, and surely a valuable addition. She must be thought of as representing the CPWG as well to the members of that board. We are fortunate to have such an active representative. Also: Although the award was directed to the board, I am sure they meant the membership; if that was not the case it should have been. Stan.

NPF Nutritional Guidelines For PD Patients

1. PD slows gastric motility. Swallowing is prolonged; the stomach takes longer to empty and food traverses through the intestines more slowly than in a person the same age who does not have PD. For this reason, the body better utilizes food when small amounts are eaten frequently rather than 3 large meals per day.

2. Most PD patients would get more benefit from Sinemet taken on an empty stomach. Taken prior to eating (even 15 minutes is beneficial), with 4-5 oz. non-dairy fluid, the pill is "washed" from the stomach through the pylorus valve and into the small intestine where absorption begins. Think of it as allowing the levodopa to get a "head start" on absorption versus the food about to be eaten!

3. If Sinemet causes nausea a small cracker or bite of fruit can be taken with any doses required between meals. Pretzels are excellent because they are portable and require no refrigeration. Ginger can also be used to offset nausea, or in prolonged cases of levodopa-induced nausea, Motilium (Domperidone) can be ordered from Canada for individual patient use. Your physician can authorize this if required.

4. Only a small percentage of patients with PD need to alter the amount or timing of protein intake to avoid interfering with Sinemet absorption. These are patients who experience significant on/of motor fluctuations, and typically take Sinemet six or more times per day

5. Weight maintenance is a problem for many PWP. Frequent, small meals may help maintain optimal weight. Liquid supplements can be useful. Sometimes patients are so diligent in limiting fat intake and worrying needlessly about protein restrictions that they deprive themselves of much needed calories.

6. Although most dietitians consider supplements unnecessary if a patient consumes adequate amount of a variety of foods, some healthcare providers view a daily vitamin and mineral supplement as a nutritional "insurance policy". This should not be a megadose formula. Take supplements with food. One regime is to take the multiple formula on Mondays, Wednesdays, and Fridays, and alternate with an anti-oxidant formula (Vit A, C, and E) on Tuesdays. Thursdays and Saturdays. It is generally accepted that free radicals are in excess and can adversely affect brain function. Anti-oxidants may help combat that process. It is crucial to note that PD patients with limited financial resources should not neglect taking adequate doses of anti-PD drugs with proven benefit in order to afford supplements, which may or may not provide significant benefit.

7. Just like other sensory processes, the natural sense of thirst diminishes with age. Anti-PD drugs also "dry out" the body. It is important to drink water "by the clock", not unlike one would schedule crucial medications. This enhances the absorption of both nutrients and medications, and reduces the risk of dehydration.

Mouse experiments link folic acid deficiency to PD

NATIONAL INSTITUTES OF HEALTH National Institute on Aging January 2002

Mouse experiments suggest that folic acid deficiency could increase the brain's susceptibility to PD, according to scientists at the NIA. In the finding, published in the January 2002 issue of the Journal of Neurochemistry, the investigators fed one group of mice a diet that included folate; a second group was fed a diet lacking this vitamin. They then gave the mice moderate amounts of MPTP, a chemical that can cause PD-like symptoms. In the mice fed folate, MPTP caused only mild symptoms of disease. But mice fed the folate-deficient diet developed severe PD-like symptoms.

The scientists found that mice with low amounts of dietary folic acid had elevated levels of homocysteine in the blood and brain. They suspect that increased levels of homocysteine in the brain caused damage to the DNA of nerve cells in the substantia nigra, an important brain structure that produces DA. Loss of DA causes the nerve cells to dysfunction, leaving patients unable to direct or control their movement in a normal manner. In mice fed adequate amounts of folate, DA-producing nerve cells were able to repair damaged DNA and counteract the adverse effects of homocysteine. However, similar nerve cells in folate-deficient mice could not repair extensive DNA damage. As a result, these cells died.

"This is the first direct evidence that folic acid may have a key role in protecting adult nerve cells against age-related disease," said Mark Mattson, Ph.D., chief of the NIA's Laboratory of Neurosciences. "It is clear from this study that a deficiency of this vitamin is associated with increased toxin-induced damage to the DA-producing neurons in the mouse brain."

People who have PD often have low levels of folic acid in their blood, but it is not clear whether this a result of the disease process or if they are simply malnourished due to their illness. But based on this study, Dr. Mattson speculates that consuming adequate amounts of folic acid—either in the diet or by supplementation—could help protect the aging brain against PD's and other neurodegenerative diseases. Green leafy vegetables, citrus fruits and juices, whole wheat bread and dry beans are good sources of the vitamin. Food and Drug Administration (FDA) regulations require the addition of folic acid to enriched breads, cereals, flours, corn meals, pastas, rice, and other grains.

Doug Dollemore **301-496-1752** dollemod@nia.nih.gov

Videos of Meetings Available at Rock Bottom Prices

Video recordings have been made of the meetings with Dr. Toni DeMarcaida, Carol Jaynes-Reiss (dietitian), and The Ladies of IND (PD research). They are available for the unbelievable price of $5 per tape. They will be available at the next meeting.

Combination of Two Widely Used Pesticides Linked to PD

University of Rochester Medical Center

Scientists have shown that the combination of two widely used agricultural pesticides-but neither one alone-creates in mice the exact pattern of brain DA mage that doctors see in patients with PD. The research offers the most compelling evidence yet that everyday environmental factors may play a role in the development of PD.

The latest findings of the team led by Deborah Cory-Slechta, Ph.D., professor of environmental medicine and dean for research at the University of Rochester School of Medicine and Dentistry, appear in the Dec. 15 issue of the Journal of Neuroscience. The scientists caution that more studies are necessary to explain the link, since it's probable that many factors contribute to a complex disease like PD, and they say it's unlikely that the pesticides on their own actually cause PD.

Cory-Slechta's team studied the effects of a mixture of two very common agrichemicals, the herbicide paraquat and the fungicide maneb. Each is used by farmers on millions of acres in the United States alone: Maneb is applied widely on such crops as potatoes, tomatoes, lettuce and corn, and paraquat is used on corn, soybeans, cotton, fruit, and a variety of other products. In the experiment, mice exposed to either one had little or no brain DA mage, but mice exposed to both share a significant trait with people in the very early stages of PD: Though they appear healthy, key brain cells known as DA neurons are dying. The mice exposed to the mixture carried nearly all of the molecular hallmarks of PD as seen in humans.

"The environmental reality is that several of these chemicals are used on the same crops and in the same geographical locations. You've got to get rid of the weeds. Then the insects, then funguses. These are different chemicals that do different things, but they're often applied in the same fields," says Cory-Slechta.

The study is one of the firsts to examine the effects of such chemicals in tandem. Cory-Slechta notes that current regulations and determinations of safety levels are usually based on the effects of single chemicals. "In the real world, we're exposed to mixtures of chemicals every day. There are thousands upon thousands of combinations; I think what we have found is the tip of the iceberg," she says. "There are a dozen different fungicides related to maneb alone. I don't think we just happened to pick the right chemicals to see such an effect."

Maneb, paraquat, and many other pesticides are used in the same agriculture-rich areas of the country, including the Midwest, California, Florida and the Northeast. The map of their use mirrors areas of the country where people are more likely to die of PD.

Several epidemiological studies have hinted at a role for pesticides in the development of PD. Studies have found that farmers, people who live in rural areas, and people who drink well water are more likely to have PD than people who don't. In addition, just last month, scientists at Emory University presented evidence that rats given a steady dose of the natural pesticide rotenone, used on homegrown fruits and vegetables, develop PD-like symptoms. Cory-Slechta's study, which used much lower levels of chemicals than the Emory research, is the first to link a combination of more widely used pesticides to PD. "No one has looked at the effects of studying together some of these compounds that, taken by themselves, have little effect," says Cory-Slechta. "This has enormous implications."

Currently scientists have little understanding of what causes PD, where a tiny group of DA-producing neurons deep within an area of the brain known as the substantia nigra die. This cell death leads to a shortage of the neurotransmitter DA and to the tremors, rigidity, and slow movement that mark PD as it progresses slowly over a period of years or decades.

There is a growing consensus among scientists that both genetic predisposition and environmental agents may play a role in PD. Doctors see a similar effect in heart disease, where a patient might have both a family history and a sedentary lifestyle, or in cancer, where certain genes may make one prone to develop colon cancer and a poor diet makes PD even more likely.

Cory-Slechta thinks it's unlikely that exposures to such chemicals actually cause PD on their own, but they may contribute to PD development. "This is the first time that truly environmental risk factors for PD have been identified," she says.

Cory-Slechta heads a research center funded by the National Institute of Environmental Health Sciences where researchers study the effects of environmental agents like cigarette smoke, air pollution, and metals like mercury and lead on human health. She believes scientists must do more research on the effects of exposure to multiple chemicals. "It's a huge problem to start thinking about a nearly infinite array of mixtures of chemicals, instead of the risk that a single chemical might pose," she says. She also says more work must be done to see how much of these chemicals people are actually exposed to. Usually it's not clear exactly how much of a pesticide remains on crops by the time they reach the dinner table. Maneb frequently shows up as a slight residue, she says, while paraquat usually shows up just in trace amounts; exposures can also occur via other routes. Oftentimes the two are used at different stages of the growing cycle. "The real issue is what happens when they hit humans in the food chain. If they're both present, then you are exposed to the combination."

In the Journal of Neuroscience paper, and in an earlier paper in Brain Research, the scientists showed how mice injected with both maneb and paraquat differed from normal mice in many ways. Most obviously, the mice moved around much less; immediately after the last of 12 injections over six weeks, the mice ran around their cages just one-tenth as much as their normal counterparts. More importantly, the mice that received both chemicals showed brain damage in exactly the same way as humans with PD did. These mice had nearly four times as many "reactive astrocytes," structures which indicate brain damage, compared to the control mice, in areas affected by PD. The mice had about 15 percent fewer DA neurons and ultimately produced about 15 percent less DA than normal mice.

The team is currently pursuing several new avenues of research, with funding from NIEHS. For instance, preliminary findings indicate that the PD-like effects on mice may be permanent, and that older mice may be more sensitive to the combination than younger mice. The team is also studying the effects of exposure to the mixture early in life, and they've shown that mice with the same genetic abnormality that causes some people to develop PD, are especially vulnerable to the mixture.

Coffee, hormones affect Parkinson's risk

United Press International Tuesday, March 11, 2003

BOSTON, Mar 11, 2003 (United Press International via COMTEX) -- Women who are heavy coffee drinkers and take hormone replacement therapy could be at a higher risk for developing Parkinson's disease, research released Tuesday suggested. For women who take HRT and drink beverages with little or no caffeine, the risk was reduced, according to the study published in the journal of the American Academy of Neurology.

Although previous studies have associated caffeine with a low risk for PD in men, data on women have been inconclusive. Dr. Alberto Ascherio's research suggests the ambiguity could be due to a previously unknown hormone factor. "Women who do not take HRT behave like men with the same inverse relationship," said Ascherio, professor of nutrition and epidemiology at the Harvard School of Public Health. Those who consumed more caffeinated drinks had a lower risk for the disease. On the other hand, "women who take HRT show an association in the opposite direction," he said.

To examine the relationship between caffeine intake, estrogen and PD, the research team looked at data for more than 77,000 women over an 18-year period. Out of these, 154 developed PD. Women on HRT who drank six or more cups of coffee a day quadrupled their risk for PD compared to those who did not drink coffee. For the moderate caffeine consumers, whether women were taking hormone therapy did not seem to affect their risk.

Acherio said further research is needed to determine what is responsible for this link. "What is well known is that estrogen delays metabolism of caffeine," he said, adding whether this plays a part in the risk for disease is uncertain. He also warned women not to change their decisions to use HRT based on these research results. "It's important to confirm these findings first," he said, as debate continues over a potential link between HRT and cancer as well as other diseases.

"It's hard to put into everyday life," agreed Dr. Charles Adler, professor of neurology at the Mayo Clinic in Scottsdale, Ariz. Although provocative, he said the results were complicated. "The major issue here is what underlies this interaction," Adler said, adding caffeine and estrogen both play roles in a number of different cell types and neuronal circuits. He pointed out the number of women who had PD in the study was small and the limited sample would affect results though they are still significant. "It adds good information," Adler said, "but for now I'd be very careful about telling people to change their amount of caffeine intake."

(Reported by Christine Suh, UPI Science News, in Washington.)

CPWG and Its Information Dissemination Initiatives **Stan Wertheimer**

In September of 2001 a plan was drafted outlining the many ways CPWG provides information to the PD and larger community. Among those activities cited were telephone contact, email contact, newsletter and information sessions, which was a new initiative we were undertaking. Several were left out, I now realize, mainly because we had not identified them or because there was no person who had one of them as a specific responsibility. Now I see that what Tom Sullivan does should be included, organizing speakers and workshops; so should Nancy O.'s work as librarian and Pat G.'s efforts in membership and label production. Jeff Lincoln, who videotapes meetings, is surely an information distributor and Jim Roy is an enabler of everyone's efforts at information distribution. Dave Curtin, who has built an index for the newsletter is surely in the same category. Now let me provide some specifics on the previously mentioned initiatives.

The draft on information sessions went on to outline the big picture for information sessions, to be held in communities around Connecticut, eventually involving the whole state. We were going to start in Guilford since it was convenient, had a high population density, and we had members who lived there - in particular Jackie Dorwin and Pam and Jeff Lincoln.

The first two sessions were a great success, reaching many newly diagnosed people in the Guilford area, but also requiring great effort on the part of Pam, Jeff, and Jackie. There were several sessions following which were much more modest in their scope but requiring great energy. One aside: The Institute for Neurodegenerative Disorders was part of the Guilford meetings and were impressed with the results, so much so that they have started similar sessions of their own and continue to hold them around the state. In this way we established a paradigm which didn't work so well for us but was picked up by another group who seem to be well satisfied with the results.

I was involved in the first three sessions as session moderator; as a result I started thinking about a better use for our time and effort. Around June 2002 I suggested that we should concentrate on getting our message out to doctors and have them let their newly diagnosed people know about CPWG and how we could help. Jackie was enthusiastic about implementing this idea too, which we had previously discussed as something we wanted to do in the future. She immediately constructed the info packets that we would try to get into doctor's offices. An important component of the plan is the involvement of our membership.

Also, about this time, the Southeastern CT Support Group, under Kit W. and Joyce B., had organized a seminar on the benefits of exercise to the PWP. It was held at the Lawrence & Memorial Hospital. It became clear that a good thing to do would be to educate the health care professionals there to the ins and outs of PD, in particular to ease a PWP stay in hospital; when I suggested this to Naomi Rachleff she agreed and put me in touch with people who have arranged our first information session for health care people. When I asked Jackie if she wanted to be part of it she jumped at the idea and immediately lined up another session in her part of the state. She also got great literature to hand out to the participants. When she gets going there is no one who works harder.

By the time this newsletter is sent we shall probably have completed our first info session for professionals. We continue to connect with people around the state by telephone and email. We publish the newsletter, to which many contribute, four or five times a year. These are the some of the ways we spread the word about PD; as I said above, there are many others. The effort is one shared by the entire membership, and that is always the best way.

Nancy and Peter O. to Host Summer Shindig

Peter and Nancy have graciously offered the use of their property to host our first annual Summer event on 19 July 2003. Their address is 9 Birch Drive, Ellington, CT. A map and/or directons will follow in the next newsletter or on a postcard announcing the event. Everyone who gets this newsletter is invited, even if you have never attended a meeting. Y'all come and meet the great folk in the group.

Gunilla Norris to Offer Tai Chi/Meditation Before Meetings

There has been steady interest in some sort of movement and centering activity at our bimonthly meetings. Gunilla Noris, a teacher of meditation as well as an author and psychotherapist, has agreed to conduct 30 minute sessions before formal CPWG meetings in Tai Chi, Chi Kung, and Shibashi as well as meditation. She acknowledges that not a whole lot can be done in that time period; she has developed a small but doable and effective set of selections from the named techniques that she feels will benefit all who take part. The sessions will be before every meeting, first one in November 2003, starting at 9:15 and running until 9:45. All are welcome. The group will meet on the second floor of Haviland Hall, probably in the Middletown Room.

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