Connecticut Parkinson's Working Group Newsletter

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The following three articles pertain to our big event for this year, following a similar effort last year. I think it is safe to say that we will be doing at least one of these a year, with a 95% probability! If you have not as yet preregistered, there is still time. There is no cost, and you get to hear internationally respected scholars discussing the latest issues in PD.

PD RESEARCH IN THE 21ST CENTURY: IN SEARCH OF THE CURE

DR. IRA SHOULSON: NEUROPROTECTION

DR. JERRY YANG: STEM CELL THERAPY

DR. ANDREW FEIGIN: GENE THERAPY

Free Admission

Pre-registration is required.

Register by phone:
(860)-343-8278
(860)-347-0134
(203)-453-2655

Register by mail:

CPWG
c/o Patricia Sullivan
94 East Ridge Rd
Middletown, CT 06457

Please fill in and tear off the registration form below.

✂

NAME(S):_____

_____

ADDRESS: _____

CITY/STATE/ZIP: _____

PHONE/EMAIL: _____

PD RESEARCH IN THE 21ST CENTURY IN SEARCH OF THE CURE Q AND A

Q: Where and when will the CPWG symposium take place?
A: On May 3, 2008 in Welte Auditorium (WA) of Central Connecticut State University in New Britain, CT. WA is located near the corner of Stanley St. and Ella Grasso Blvd Look for events signs pointing the way. Use the following web address for directions: *http://www.ccsu.edu/Viewbook/find_us.htm* The program will begin at 10:00 am; the doors will open at 9:00.
Q: Where will I park?
A: Next to WA is the WA parking garage, which has a fully accessible elevator. You can park there or in the large parking lot behind WA. Parking is free.
Q: What if I am having difficulty walking or "getting around" that morning?
A: The parking garage would be best for you. The elevator there drops you off a short way from the main entrance to WA. CPWG will have wheelchairs and people to assist those who need help. Go to the bottom floor of WA garage, near exit and look for a CPWG volunteer.
Q: Is there an admission charge?
A: No.
Q: Is there any handicapped seating?
A: Yes, there are designated areas, specifically designed for wheelchair seating. Ask an usher for assistance. WA is fully accessible.
Q: Can I still register for the symposium?
A: Yes. Call 860-343-8278, 860-347-0134 or 203-453-2655. You may also register on the day at the door.
Q: Can a person not diagnosed with PD attend?
A: Absolutely, CPWG encourages anyone interested in PD to attend.
Q: Will there be any displays or information tables?
A: Yes, from our corporate sponsors, and from CPWG.
Q: When will the program conclude?
A: It s scheduled to end by 1:00 pm. You are free to view information tables, booths or displays in the Lobby and in the courtyard.

PARKINSON DISEASE RESEARCH IN THE 21ST CENTURY—IN SEARCH OF THE CURE

CONNECTICUT PARKINSON'S WORKING GROUP SPONSORED SYMPOSIUM

On Saturday May 3, 2008, the CPWG is sponsoring its second scientific symposium, and all members of the Parkinson community, (diagnosed people with PD, family, caregivers, medical professionals, and researchers) are invited to attend. CPWG continues the formula of inviting the most respected PD experts as panelists. This year we ask the question that is paramount in so many people's minds—"Will we find the cure?" The symposium will be held on May 3, 2008 in Welte Auditorium located on the Central Connecticut State University campus in New Britain, CT. There is no entrance fee for the symposium, which will begin at 10:00 am and run until approximately 1:00 pm. However, it is necessary to register with CPWG and it is not too late to sign up. Register by calling (860)-343-8278 or (860)-347-0134 or (203)-453-2655.

To respond to our question, we have asked three leading researchers in fields that are presently thought to be the most promising for a breakthrough in potential PD modifying trials—neuroprotection, stem cell therapy, and gene therapy.

Ira Shoulson, M.D. is considered THE expert to whom all other clinical researchers turn for guidance when attempting to design or decipher a reasonable neuroprotective study. He has been conducting clinical research in PD since the 1970s.

Dr. Shoulson is Professor of Neurology, Pharmacology and Medicine at the University of Rochester Medical Center, Director of Experimental Therapeutics (ETh), Louis C. Lasagna Professor of ETh, and long time Chair of the Parkinson Study Group (PSG). He has been the mentor of mentors in his dual role as Director of the Movement Disorders and ETh fellowship program at Strong Memorial Hospital, and as long-term chair of the PSG, a cooperative group of PD experts from medical centers across the United States and Canada who are dedicated to conducting the highest quality clinical research studies to improve treatment for patients with PD.

He has been the Principal Investigator for countless multi-center clinical trials examining the symptomatic and neuroprotective effects of experimental interventions in PD. He will discuss clinical research today in neuroprotective or disease modifying trials.

Andrew Feigin, M.D. is Associate Professor of Neurology and Associate Director of the Movement Disorders Center of North Shore LIJ. He heads the Neuroscience Experimental Therapeutics Division of the Feinstein Institute for Medical Research, with specific interest in using state-of-the-art imaging methods to develop new therapies for PD, Huntington disease, and other Movement Disorders. He is a leading investigator for many clinical trials of new treatments for PD, and was one of the leading authors of the recent article in the Lancet Neurology reporting what is considered a major breakthrough in the treatment of PD using gene therapy. Dr. Feigin will discuss the exciting news about gene therapy that was published in this article.

With such a distinguished panel discussing the ultimate question in our minds, the CPWG is proud to present its second effort in two years to inform and educate. Save May 3, 2008 from 10 am to 1 pm for this symposium to be held in Welte Auditorium at Central Connecticut State University in New Britain. Registration for this event will begin on February 1, 2008. Register by calling CPWG at (860)-343-8278 or (860)-347-0134 or (203)-453-2655.

The Connecticut Parkinson's Working Group is a state wide organization that has as it's mission supporting and educating people who live with Parkinson disease on a daily basis—PWPs, their caregivers, family, friends and the medical professionals who research and treat Parkinson disease.

Note on following article: There seem to be several common compounds that reduce risk of PD. Among them are coffee and cigarettes; these two seem to be at the choice of the person. So, is it use of the compound (java and butts) or the personality of the person who uses it, or some other reason? In the following, involuntary use of s calcium channel blocker seems to do the same thing. What is it about these compounds that gives them this preventative edge? Stan

HIGH BLOOD PRESSURE PILL CUTS RISK OF PD

ScienceDaily February 9, 2008

People taking a widely used group of drugs known as calcium channel blockers (CaChB) to treat high blood pressure also appear to be cutting their risk of PD, according to a new study.

The study involved 7,374 men and women over age 40. Half of the group had PD; the other half did not. Among both groups, nearly half used high blood pressure medications, such as CaChB, ACE inhibitors, AT II antagonists and beta blockers.

The results of the study were reported by tudy author Christoph R. Meier, PhD, MSc, with University Hospital Basel in Switzerland: "Long-term use of CaChB was associated with a reduced risk of developing PD while no such association was seen for other high blood pressure medicines".

Meier says more research is needed to determine why CaChB appear to protect against PD, whether this is indeed a causal association, and why the other high blood pressure medications do not offer a reduced risk.

GOVERNOR RELL: STATE ALLOCATES $9.84 MILLION IN STEM CELL RESEARCH FUNDS

Governor M. Jodi Rell today announced that the state's Stem Cell Research Advisory Committee has directed the allocation of $9.84 million in stem cell research funds to scientists based in Storrs, Farmington and New Haven. "Connecticut remains at the forefront of investing in and supporting cutting edge research in this emerging field," Governor Rell said. "The stem cell research that this year's grant recipients will undertake is meaningful to the state not only because of its potential public health benefits but also because it may lead to significant job growth in Connecticut."

This is the second installment of grants from the Stem Cell Research Fund created by a law Governor Rell signed in 2005. Between now and 2015, the committee is tasked with allocating approximately $100 million in order to encourage stem cell research in Connecticut.

Eighty-seven stem cell funding applications were accepted for consideration in November 2007. From December through February, a 14-member Connecticut Stem Cell Peer Review Committee reviewed these applications in accordance with National Institutes of Health guidelines and provided to the Advisory Committee its recommendations with respect to the scientific merits of each application.

DR. KENNETH MAREK, AN INTERVIEW
by Jeff Lincoln

Dr. Ken Marek (K) is the President and a founding member of The Institute for Neurodegenerative Disorders (IND) in New Haven, Connecticut. IND is a research driven group, with a major interest in Parkinson's Disease. K has wide experience in neurology and extensive research into Neurodegenerative Disorders. Jeff Lincoln (J) is the interview editor for the CPWG Newsletter.

J: Were you born a neurologist working on Parkinson's Disease (PD)?

K: Actually, I was.

J: I guess that's the end of the interview. Seriously, tell about your background.

K: I have had a great interest in how the brain works for many years, first in college and then in the lab as a biochemist. PD is an area in neurology that intersects most clearly with neurochemistry because we know in PD what the neurochemical problem is. We know that Dopamine is important. PD was a good model for someone who was beginning to understand how to use brain chemistry techniques in studying neurological diseases. Hence my interest. Movement disorders is one of the last areas in neurology where the physical exam tells you most of what is happening to the patient. It is an old fashioned approach to neurology. In people who have strokes or epilepsy, we do not just rely on physically examining the patient.

J: Where did you get your MD?

K: At Yale, in 1978. I then did my medical internship at Johns Hopkins, followed by two years of research at the University of London's neurological hospital, Queen's Square. Our lab group was interested in Alzheimer's disease. After that, it was back to Yale for a degree in Public Health and then to Hopkins again to complete my residency in Neurology. I spent five years on their Faculty and ten on the Yale Faculty.

J: So you were at Yale New Haven Hospital.

K: Yes, for about ten years I ran the Movement Disorder Clinic at Yale. About seven years ago, with some colleagues, I formed IND. The reason was to enable us to do research in PD and related problems more effectively. One of the issues you have to contend with at a University, is that your time is split between providing clinical care, doing administrative work, and doing research. It was frustrating. I decided it would be more desirable to do research full time, and was able to organize IND around that approach. It has been productive, wonderful. In a University setting, every six or seven years you can go on sabbatical and focus on your research. At IND, it is like being on sabbatical all the time. As long as we can come up with the funds, we can concentrate on our research all the time. It is enjoyable.

J: Over the years, I've interviewed most of the MDs at IND. I left you for last because, more than anyone else, you set the vision for IND.

K: The vision is to be able to address the question, "How can we move the field forward?" We can do this in many ways: by identifying new medicines, by developing new tools to evaluate PD, and by making research opportunities available to people in the community. Our overriding mission is to do research in this area so that we will understand the disease and be able to treat it better and earlier.

J: Has the climate for PD research changed in the last five years?

K: Not in five, but in the last ten years, there has been increased interest in PD research. There are many organizations interested in this work. People have become more realistic. Ten years ago there was a lot of discussion about the disappearance of PD. We would like to see that happen, but it is unlikely that someone will suddenly find a cure. Hard work is involved in achieving small advances in the treatment of PD and how we care for PWP. There have been substantial changes in the last decade in how we treat PD and these are reflected in how people do. If you ask a group of PWP today or the MDs who treat them, most feel that PWP are doing better. That's not to say there aren't many, many challenges that need to be sorted out, but I believe that it will happen one step at a time.

J: Could someone sneak in the back door with a miracle cure developed from the "rat model"?

K: That would be great. There is no doubt that it is a possibility. But most likely, we will progress at a steady but deliberate pace

J: New subject: I have heard that you are expanding into Europe to work with colleagues there. How is that going?

K: We do have collaboration with many European investigators and have developed a group of about twenty-four sites with physicians interested in brain imaging. We are leading this consortium of sites in PD research. One of the nice things about current PD research, is that there is a lot of good collegial collaboration between the United States, Canada, Europe and Japan. The sharing of ideas helps the field to move ahead more rapidly.

J: Do you have SPECT apparatus in Europe?

K: Yes, the SPECT (Single Photon Emission Computed Tomography) is simply a nuclear medicine technique that enables us to identify abnormalities in the brain. We have recently expanded to do PET scanning (Positron Emission Tomography). These machines are in the U.S. and Europe.

J: What about IND's involvement with disorders other than PD?

K: We deal with other Neurodegenerative diseases, by which we mean those where there is a slow loss of nerve cell function in the brain. The most common of these is Alzheimer's, with PD being the second most frequent. Alzheimer's is an interesting problem in itself, but there are also commonalties between these two diseases, both in the pathology and in how they affect the brain's progress. Imaging tools that we use for PD are now being used in Alzheimer's research as well. One of the big things we have learned about PD is that it is not only a problem of movement. In many people it is a problem of thinking. We would like to know why some PWP get this symptom and others do not, and how this can change. What is the relationship between PD and Alzheimer's in those people? These questions connect the two disorders.

J: What advice would you give about clinical trials to a newly diagnosed PWP ?

K: We see many newly diagnosed people. The first piece of advice would be to learn as much as they can about PD, to take some time and think about what they want to do next. Do they want to get treatment or not? They should give themselves at least a month to sort out where they want to go with that. It is important to give newly diagnosed people the sense that they have time to make decisions. Secondly, IND is focused on doing research, so my own bias is to encourage them to consider participation in clinical trials. That's how we are going to advance the field. Clinical trials can also help the PWP to understand the disease. Thirdly, PWP in trials get lots of attention. This helps them to feel more comfortable as time goes on. Clinical trials are not for everyone, but they are certainly something to think about. There are all kinds of trials and some that do not require meds. We learn a lot from those involved in a trial.

J: Would you caution people about clinical trials?

K: It's important to know that there may be a period of time in which they are not getting the drug, just a placebo. If they need that med, it might not be appropriate to be in that study. There are risks in clinical trials. In most trials, the risks are modest because they have been given to a number of people already. Some of the risks are known and some are unknown. One needs to make the decision that he or she is willing to accept these risks.

J: Where is research going in the next five years?

K: Research is going on in many places but there are two major categories. The first is to find ways to improve or restore function in a PWP. Gene therapy is emerging and there are two or three trials underway. We will hear more about GT as we know more. We must also start treating symptoms other than motor problems, such as cognitive, emotional, and bladder or bowel functions. For us, the second category is an exciting area of research with people who do not have PD but might be at risk of developing it. We are on the brink of developing tools and methods we need to identify those who might be at risk. We then have the potential for preventing PD—it is exciting. We would like to see PD treatment before symptoms arise and then, if necessary, prevent those symptoms from worsening. At IND we are taking a three-pronged approach. First, we are looking at people who are relatives of PWP. Next, we ask them to do a smell test. Some have abnormal olfactory function and are then asked to come in and have brain imaging. If they have abnormal imaging also, can we say "You are at risk for PD. You ought to be treated with an appropriate medicine today."? Not yet, but that's the goal. There is an enormous amount of research to develop simple ways to identify whether someone might be at risk for developing PD. These are called biomarkers. Some are in blood, some in urine, and some in spinal fluid. There are myriad ideas about this approach. Right now, none of these tools lead to a definitive PD test. We expect progress in the next several years. There would be great benefit to be able to identify those likely to get PD.

J: Are there any new diagnostic tools coming down the pike?

K: A number of these tools could become diagnostic tools. It's one thing to use these in a research effort and another to use them as a diagnostic tool for everyone. We're not there yet. Imaging is clearly the closest to becoming a diagnostic tool.

J: I understand there are two trends here: First, to identify who has or may have a higher risk of PD earlier in the course of the disease; and Second, to slow down the progression of PD once it has been identified. Putting those two together would not be a cure but would go a long way toward making a PWP feel cured.

K: Conceptually, yes. If you have a disease like PD, which is slowly progressive, and you could change the rate of progression so that it is one half the rate it is today, then the PWP is not cured, but has a higher quality of living. One of the things that is so important, as we said earlier, is for a PWP to think about research.

Right now less than 1% of PWP are involved in research activities. Yet we all would like to see an acceleration of the research process. One way to increase the speed of Clinical Trials is to sign up more participants faster. If a trial takes one year, we cannot close that trial until the last participant completes the activities. An increase of 1 or 2 % participants could cut the study time by up to six months.

J: Is there any message you would like to leave as we wrap up the interview?

K: Again, the message is one of hope, one of continued improvement in treatment, and of an incredible robust research environment that continues to amaze me with all kinds of new ideas. There will be important and useful changes for PWP. Be Optimistic!

J: Thank you for your time and the insights you have shared with us.

PD DISEASE LINKED TO PESTICIDE EXPOSURE

Medical News Today, 28 Mar 2008

New research from the US has suggested that patients with PD were significantly more likely to have been exposed to pesticides than unaffected family members.

The study is published in the open access online journal BMC Neurology and is the work of investigators from the Duke University Medical Center in Durham, North Carolina, and the University of Miami Miller School of Medicine Morris K Udall PD Research Center of Excellence in Miami, Florida.

There are approximately 1 million Americans living with PD, a common neurological disorder that typically starts in later years and whose symptoms include tremors and rigid muscles. Some studies have found rare gene variants account for a small percentage of overall cases, but most are believed to arise from the interaction of genes with the environment.

Lead author Dr Dana Hancock explained that: "Previous studies have shown that PWP are over twice as likely to report being exposed to pesticides as unaffected individuals. But few studies have looked at this association in people from the same family or have assessed associations between specific classes of pesticides and PD".

By examining family members who shared a potential genetic predisposition to PD, the investigators were able to look for differences in environmental exposure between those members that had the disease and those that did not.

Hancock and colleagues recruited 319 PWP and over 200 of their relatives and interviewed them on the phone to find out how they might have been exposed to pesticides, such as from handling or being exposed to specific types, or by working or living on a farm, or drinking water from wells.

When they analysed the results they found a signficant link between pesticide exposure and PD. The strongest link was between the disease and exposure to herbicides and pesticides like organochlorides and organophosphates. No significant links were found between PD and well-water drinking, or living or working on a farm, which are often described as "commonly used proxies for pesticide exposures".

Commenting on the findings, Hancock said that many studies have suggested pesticides as a risk factor for PD, but like this one, they lack the biological evidence. She called for further studies to look more closely into the biological mechanisms linking pesticides to PD, and that future genetic studies should consider the possibility that pesticides may trigger PD in people with a genetic predisposition to the disease.

"Pesticide exposure and risk of PD: a family-based case-control study."

Dana B Hancock, Eden R Martin, Gregory M Mayhew, Jeffrey M Stajich, Rita Jewett, Mark A Stacy, Burton L Scott, Jeffery M Vance, William K Scott.
BMC Neurology 2008, 8:6.
Published online 28 March 2008.
DOI:10.1186/1471-2377-8-6

MANUFACTURER OF THE PD PATCH ANNOUNCES RECALL OF US BATCHES BECAUSE OF CONCERN ABOUT EFFECTIVENESS; ADVISES PATIENTS TO SEE THEIR DOCTORS

UCB Inc., the company that manufactures rotigotine (Neupro®), the transdermal patch treatment that is used to ease the symptoms of PD in its early stages, has announced a recall of all Neupro batches in the U.S.A. and some areas of Europe.

The company has assured the public that the recall has been made not because of concern about contamination or toxicity, but because of a deviation from approved product standards that has apparently reduced the effectiveness of the treatment.

Because correction of the problem and the replenishment of the batches will take time, patients on Neupro are being advised to contact their health care professionals to arrange for their doses to be reduced slowly over time, as advised on the product label. The company advises strongly against sudden discontinuation.

Dr. Christopher Goetz, Director of the PDF Research Center at Rush University Medical Center in Chicago , says that for patients now on Neupro, the physician may recommend switching to one of the oral medications known as dopamine agonists that are in the same drug class as Neupro.

The PDF website will continue to keep readers informed as the supply situation, and the company's response, become clear. (*http://pdf.org/*)

Comment on the following: The net article outlines what sounds like a fine program for any PWP who has the time to participate and the desire to do the kind of thing that the CPWG has been doing for eight years. It is a "course for those who want to be involved with CPWG to help them do what is in their Mission Statement".

CLINICAL RESEARCH LEARNING INSTITUTE (CLRI)

The CLRI provides people with Parkinson's with the knowledge and skills necessary to be effective representatives within the clinical research enterprise. The 2008 Institute will take place from Thursday, July 10 through Saturday, July 12 in Glen Cove, NY.

Why a CLRI for People with Parkinson's?

Creating a place at the table for people with Parkinson's disease (PD) to share their viewpoints and experience is critical to moving the development of treatments for PD forward — yet it is all too often overlooked.

PDF recognizes the important role that people with PD can play in the clinical research process and in 2008, launched the CLRI. The goal of the CLRI is to provide people with Parkinson's with the knowledge and skills necessary to be effective representatives within the clinical research enterprise.

The new CLRI is part of PDF's Advancing Parkinson's Therapies (APT) initiative, a multi-pronged program that addresses non-science barriers to the acceleration of PD therapies and treatments.

What is the CLRI?

The PDF CLRI is a multi-day training that prepares people with Parkinson's disease for such activities as: educating the broader community about the importance of clinical research; providing research sponsors and investigators with input on trial design, implementation, and evaluation and serving on Institutional Review **Boards (IRBs) and Data Monitoring Safety Boards (DMSBs).**

Experts from all sectors of the clinical research enterprise — including researchers, trial coordinators, and government and industry representatives serve as faculty for the CLRI. CLRI participants will have the opportunity to engage in continuing education activities and ongoing communications with other graduates. The CLRI takes place once per year and participants are selected through a formal application process.

Interested in Participating in the CLRI?

The inaugural CLRI will take place Thursday, July 10 through Saturday, July 12 in Glen Cove, NY.

Apply

If you are a person with Parkinson's who is interested in participating in the Clinical Research CLRI, please contact Nicole Rabin, National Programs Coordinator at (800) 457-6676 or nrabin@pdf.org.

Questions

If you have questions about the CLRI, please contact Veronica (Ronnie) Todaro at rtodaro@pdf.org or (800) 457-6676.

CONNECTICUT PARKINSON'S WORKING GROUP

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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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Russell Senate Office Building
Washington, D.C. 20510

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Hart Senate Office Building
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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 “@”.