



Connecticut Parkinson's Working Group Newsletter

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Donations from the CPWG community support this newsletter, published 4–5 times annually. The Staff hopes to keep the reader up-to-date on issues concerning PD while raising her understanding of the disease. We urge you to email comments and suggestions to us (electronically, text only); we will try to include these in future newsletters. Please note that we are not interested in reporting on the achievements of donors, walkathons or galas, etc. We will edit existing articles of interest to our readers, always crediting the source. Visit our website for more information about CPWG and how to donate: www.cpwg2000.org.

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GOTTA DANCE!!

We are ready to inaugurate the first dance class for PWP in Connecticut. The instructor, Katie Tranzillo, has conducted one session for us at the meeting time and will do another on March 21 at 11:30 at Vinnie's dance studio on Main Street in Middletown, CT. Come and sample what she plans for her classes.

Katie will hold class for six weeks, one per week, starting on March 24. There is no fee for any PWP AND partner; since membership in the CPWG is by fiat, this means anyone with PD is welcome. Also apparent mobility is not an issue (wheelchairs are okay). The schedule is: Tuesday 3:30—4:45 PM at Vinnie's on Main Street in Middletown (just South of Route 66) : March 24, 31 April 7, 21, 28 May 5. That is, it will meet every week from March 24 to May 5 except for April 14.

We expect this effort to continue, as has the Mark Morris Dance Group's {MMDG} program in Brooklyn, NY. They are responsible for a groundswell of interest and new programs in dance and PD throughout the country. They were featured on a PBS radio program; we have a video which is available online at PBS.org for viewing. One can feel the excitement, and, of course, hear the enthusiasm in the comments of those involved.

Our plans, although embryonic, are to have two classes in place and running by the end of the year. Katie's will be the first, in Middletown. We are working on a second in Southeastern CT, New London probably. We have the interest of a college in that area, and some excellent possible instructors; it is only a matter of time before we can start there, we hope.

This newsletter will carry articles, references, letters, and other written items about dance and PD as a priority in the future. If you "gotta dance", want to find out what all the hype is about, want a fun form of physical exercise, or are just looking for a good time, come to the dance classes at Vinnie's, and do not forget that the CPWG is the sponsor, and at present the sole supporter. There are no costs associated with this class. This is a pilot project—Katie has every intention of going on after May 5 and the CPWG will support her classes. The stop after six classes is to assess the hours, room, location, and other aspects of the course, by participants and Katie, to see if it can be made better. She is even willing to move her location.

GOTTA MEET!

Both Tom Sullivan and Jackie Dorwin are promoting activities that help people get together to talk, that most important activity that sometimes we do not do often enough. Tom is continuing his successful "breakfasts" initiative, where he designates a restaurant and a time and tells those nearby about it—they can be there and share their thoughts with others if they wish.

Jackie has organized women's and men's meetings at her house, where the genders can address issues specific to their sex. If you want to participate, by attending, or organizing either a breakfast in your area or special meeting, contact one of them to get details on how best to go about it. We at the newsletter will cooperate in any way we can.

Comment: The following results are not new—they have been known for several months; however, it is important enough to include for those of us that missed it. It represents yet another setback for GDNF and GDNF-type drugs and their clinical trials. If you recall, nineteen years ago, primates were “cured” of MPTP induced PD by GDNF. Unfortunately, we are just that much different so that it does not work for us—yet. This statement comes from the PDF and its Executive Director. The original is at their website.

CEREGENE PHASE II TRIAL RESULTS

We have just learned that the widely-watched clinical trial of a potential new gene-therapy treatment for Parkinson’s disease (PD) has shown no evidence that the treatment works. Ceregene Inc., the company that was testing the efficacy of neurturin, or CERE-120, reported today that a Phase II trial testing the efficacy of the treatment “did not demonstrate an appreciable difference” between the experience among patients with PD treated with neurturin and the members of a control group. A total of 58 people were part of the trial testing the efficacy of neurturin, which is a growth factor similar to GDNF that is delivered using a viral gene therapy technique.

Many members of the Parkinson’s community had pinned hope on the experimental treatment and its potential to ease the symptoms of Parkinson’s. Jeffrey Ostrove, Ph.D., Ceregene’s president, expressed his thanks on behalf of the company to the patients, physicians and staff who participated in the trial, and said he “shared their disappointment.”

We at PDF are also deeply disappointed, on behalf of the many thousands of people with Parkinson’s who look to us for guidance and of the scientists with whom we work. The trial was one of the most promising around, and it was in the hands of principled, professional people and gifted scientists. Our hearts go out

especially to the courageous men and women who participated in the trial. The news offers us yet another lesson—the latest, I am afraid to say, in a string of such lessons over the past several years—in how difficult, how uncertain, how frustrating, is the process of clinical research. In the cause of making sure that every new treatment that hits the market is both safe and effective, we live by a process that takes years to deliver results, costs millions of dollars, and is always subject to potential disappointment. But hard as it is sometimes to admit, we do not have an acceptable alternative to the randomized, double-blind, placebo-controlled trial, and we must live by its results.

The company has not yet released the data from trial, and so we have nothing further to report to you at this time. As soon as we learn more, we will be sure to post it on this site. On a brighter note, I remind you that the Ceregene trial is not the only game in town. In two recent articles that appeared in the PDF newsletter*—one authored by Mark Sommer, M.D., M.P.H., and Mark Stacy M.D., of Duke University and the other by Marina Emborg M.D., Ph.D., of the University of Wisconsin—some of the new directions in research were summarized. You may find it heartening to check them out.

*Robin Elliott, Executive Director,
Parkinson’s Disease Foundation*

ORION: PRIMARY OBJECTIVE OF STRIDE-PD STUDY WAS NOT ACHIEVED

The result of the primary endpoint measured in STRIDE-PD, a clinical study with Orion’s proprietary drug Stalevo® (levodopa, carbidopa and entacapone) in 747 patients with early PD (PD) requiring levodopa treatment, demonstrates that Stalevo does not delay the onset of involuntary movements, dyskinesia. The study was aimed to provide support for extending the current EU indication to early PD.

<http://www.orion.fi/english/investors/stockreleases.shtml/a04?27613>

SCIENTISTS’ STEM CELL BREAKTHROUGH ENDS ETHICAL DILEMMA

Scientists have found a way to make an almost limitless supply of stem cells that could safely be used in patients while avoiding the ethical dilemma of destroying embryos. In a breakthrough that could have huge implications, British and Canadian scientists have found a way of reprogramming skin cells taken from adults, effectively winding the clock back on the cells until they were in an embryonic form.

The work has been hailed as a major step forward by scientists and welcomed by pro-life groups, who called on researchers to halt experiments which use stem cells collected from embryos made at IVF clinics.

<http://www.guardian.co.uk/science/2009/mar/01/stem-cells-breakthrough>

AN INTERVIEW: DONNA DIAZ WITH JEFF LINCOLN



12/13/2008

Donna Diaz (R.N., M.S) has been the Information/Referral Center (I&R) Coordinator for the American Parkinson Disease Association (APDA) program at St. Raphael's Hospital for over twenty years. During that time she has worked tirelessly to improve the quality of life of people with Parkinson's Disease (PWP).

J. What drew you to PD, and in working with PWP?

D. My passion for PD grew slowly. When in nursing school, I diagnosed my grandmothers with PD. We had just learned about neurological disorders; when I saw my grandmother, 70 at the time, I told my father that she had PD. He laughed ; we all had gall bladder problems a few months ago when I studied GI disorders. But she did have PD; he was her care giver for the next 19 years.

J. How did you become involved with PD?

D. Fast forward to twenty years ago. I had been working as an evening nurse at St. Raphael's Hospital. I needed to change my hours so I could be home for my daughters. I saw a job posting that the hospital was looking to start up a PD program, sponsored by the APDA. They wanted a Nurse Coordinator, twenty hours per week to run this program statewide. I had been a critical care nurse, head nurse of an ICU, and I had experience in nursing education. I applied and was hired. I thought this would do for a few years. That was October of 1988! I do it because I feel I can help PWP live better lives. I, too, am enriched.

J. What do you consider your primary role?

D. Outreach, for the state, for PWP, their family members, the general community, and healthcare professionals. I deal with education and advocacy; but I am also the coordinator of an I&R center. There is a lot of information to share, a virtual explosion in the last 8 years.

J. If a newly diagnosed PWP comes to your office, what process do you go through?

D. People don't do that. Most triage (first look) is by phone or the Internet. Typically, I get an email requesting a packet of information. I do a telephone assessment—Who is this person? His/her significant others? How old? how long diagnosed? medicines, etc.? I want to see if they are ready for all this information. Not everyone needs the whole Welcome package; it can be overwhelming. Other questions: Is the diagnosis adequate? Have they gotten needed referrals? Sometimes I suggest the person get a second opinion. People are sometimes misdiagnosed. I listen, apply my experience, and if something doesn't sound right, I will do what I have to, to make sure that they are on a sound medical path. If all seems fine many PD resources become available: e.g. support groups, and research facilities, etc.

J. What do you see as the climate for PD research in Connecticut?

D. Over the past eight years the folks at the Institute for Neurodegenerative Disorders (IND) have flourished. I see more Movement Disorder Specialists; many who run clinical trials. It would be wonderful if one day we could have a movement disorder center devoted to clinical research *and* outreach. It would help both PWP and health care people. Right now, I treat each person individually (age, when diagnosed, what stage, interest in research) and recommend research. As you know, not every PWP is ready to participate in clinical trials, which we all know are crucial to making progress in treatment and finding a cure.

J. Do you caution people about doing research?

D. I refer them to pdtrials.org. Anyone thinking of doing a trial should be aware of the time and effort required. There is usually information on the trial, on the web. Most trials are stage 3, and so probably safe. I also point out that they might get the placebo.

There has been progress in treating symptoms of PD; we still do not know the cause. PD is no longer your Grandmother being 75 years and having a little tremor. Although we have not found a cure, we have developed better tools for symptomatic relief. Fifteen years ago there were a half-dozen drugs; now there are two pages full.

- J. There are so many choices now that you have to be your own advocate. Even denial is a okay when there is no known cure.
- D. I would never have understood this until recently. There must be a reason that denial is part of human makeup; I believe that it is to help us manage our journeys through life.
- J. Tell me more about the APDA.
- D. The missions of the APDA are: to find the cure for PD; to ease the burden until that happens. Finding the cure is clear, but easing the burden is complex; the APDA wants to create grass roots groups. They start with small centers, usually funded by and affiliated with a local hospital. There is usually one center per state. A nurse, social worker, or allied health provider who is committed to our mission is selected to run each program. Here in Connecticut we evolved from a small group around New Haven to having over 20 support groups in the state, each different with its own personality. Whether in a group of 7 or 480 [such as the bi-annual meeting at Sturbridge, MA -Ed], its important to bring people new information. I consider it a privilege to work with support leaders and people like you who are volunteers; the ADPA position makes that possible. The APDA grant pays my salary and St Raphaels covers my phone and office expenses; we get a lot done with little funding. But there is more that could be done.
- J. Is there anything you wish to add as a final comment?
- D. I feel deeply about this: I've stayed eighteen years beyond the two years commitment I made when I started; the people in the PD community area wonderful. I've never met a PWP I didn't like. I hope to see advances from medical research (find the cure), but as a nurse, I see my role as being able to make life with PD better on a day-to-day, hour-by-hour basis so that PWP can live at home, get out into the community and be safe (ease the burden). We are all working at that together. When I give talks, I often say, *It's a better time than ever to have PD*. What I mean is that the richness of support available continues to get better. Until there is a cure, what more can we ask?

NEW CLINICAL LEARNING PAGE IN THE CPWG NEWSLETTERS

Starting with the next newsletter there will be a page devoted to the clinical trials being conducted in the state. There are several centers of research activities we shall give you reference to, with the kind of trials they are doing. We hope this will improve the number of people considering being a subject.

LETTERS TO THE EDITOR

We are getting some long awaited feedback in the form of letters—hooray! This adds much to our newsletter, as do unsolicited position pieces (Op Ed, sort of). More about dance and PD a little later. I hope someone can help Deborah.

To the Editor:

My husband is 87 and was diagnosed with PD nearly 3 years ago. He enjoyed dancing and often laments that he is no longer able to do so. There was in interesting article about dance and PD patients on page 3 of the last newsletter. These classes are currently being conducted in Massachusetts.

I am writing to inquire if there is any such group in Connecticut? It is enlightening to receive encouraging news about various treatments for PD, but ultimately

frustrating if such help is not available in Connecticut! I compare it to learning that there is a cure for whatever ails you, but only if you travel to Hong Kong, then remain a year to take advantage of it.

Please keep us all posted on any inroads to forming classes in Southeastern Connecticut.

"Time flies, heaven invites, hell threatens" Tom Wolfe

Cordially,
Gail Caddell

To The Editor:

I have been receiving the Newsletter and it has been informative; it is nice to know that there is a network of people out there who understand and care. That is one of the reasons for this e-mail.

I am hoping that you (and the CPWG) might be able to help me find a neurologist in New Haven/Hartford County who specializes in or is familiar with PD. My current doctor will not be in the medical network of our new medical carrier.

I am no longer working and my husband is planning on retiring soon. We cannot afford to pay full medical charges; the doctors need to be in-network. Do you, the CPWG, or any members have a list or know of any neurologists whom they would recommend? The IND doctors are all wonderful but I believe that none are taking on new patients. The following is a brief note that, if some members respond, might help me solve my problem. If you are able to help; my email address is c2chin@aol.com

Ten years ago I was finally diagnosed with early onset Parkinson's. My first neurologist didn't believe that there was anything wrong with me when I told him that something was just not quite right with my body but there were no supporting typical symptoms. One year later my new neurologist sent me to the local PD experts and researchers at IND to confirm her suspicion that I had PD. Now 10 years later due to employer changes in Health Care carriers and providers, my neurologist will no longer be covered under our plan. Hence this e-mail request.

How long have you been associated with your current neurologist?

What do you like about your doctor? How would you describe him?

Would you recommend you doctor to your best friend?

Sincerely,

Deborah S.

Comment: The next entry gives an example of how who we choose to run the country affects us in personal ways beyond politics. It also points out that certain organizations, the PDF here, are doing what they say they are doing; be careful to investigate any organization, no matter how legitimate the name sounds, before you donate. I know of some that are outright scams. You are advised to put groups like The Michael J Fox Foundation, the PDF, the NPF, the APDA, and of course the CPWG at the top of your list. Finally, these research projects are all on the cutting edge. Stan

PARKINSON'S DISEASE FOUNDATION AWARDS \$300,000 IN BRIDGE FUNDING FOR INNOVATIVE RESEARCH PROJECTS

New York, NY—Feb 19 2009

The PDF has awarded \$300,000 in emergency bridge funding to four leading PD scientists. The grants will sustain promising investigations that were recently put into jeopardy by the sudden collapse of their primary private funder, The Picower Foundation, whose endowment was managed by Bernard Madoff; it was forced to stop all grantmaking activities as of the end of 2008.

The awards will support four innovative research projects with one-time grants of \$75,000 each. The four lead scientists are known for their outstanding work in PD:

J. Timothy Greenamyre, MD, PhD, of the U of Pittsburgh School of Medicine,

Virginia M.-Y. Lee, PhD of the U of Pennsylvania School of Med,

David Sulzer, PhD, of Columbia U Med Ctr

D. James Surmeier, PhD of Northwestern U Feinberg School of Med.

Each project is pursuing a novel avenue of research that may shed light on new ways of treating PD.

Dr. Greenamyre will test several classes of medications already approved by the FDA for diseases other than PD to observe whether they are effective in improving gastrointestinal motility in PD. Despite the frequency and debilitating nature of this nonmotor symptom for people living with PD, there are no drugs designed specifically to address it.

Dr. Lee, along with John Q. Trojanowski MD PhD, is focused on drug discovery, targeting the misfolding, or clumping, of a protein called alpha-synuclein. This clumping is believed to contribute to the cell death that leads to PD. Their team will test a variety of known compounds to determine if any are effective in preventing the protein clumping and will examine the most promising candidates for their potential to not only treat PD, but also to theoretically slow its progression.

Dr. Sulzer will investigate the role that inflammation, caused by an immune response, plays in causing the death of neurons in PD. Scientists already know that inflammation occurs in areas of the brain affected by PD and suspect that it may trigger cell death. By taking a fresh approach to understanding how inflammation is

initiated, Dr. Sulzer's work may yield a better understanding of how PD develops, pointing toward new ways of treating the disease.

Dr. Surmeier will explore the idea that areas of the brain affected by PD, some of which have not been traditionally studied, may share a common mechanism that contributes to the death of neurons. He hypothesizes that this mechanism may involve excess levels of calcium inside cells. If Dr. Surmeier's high risk approach is on target, he says it may be easy to identify a treatment that could concurrently ease the motor and nonmotor symptoms of PD, something that is not feasible with current therapies.

Dr. Lee, of the U Penn School of Medicine, noted, "With PDF's help, we will be able to continue our research, the ultimate goal of which is to expand the 'pipeline' of promising compounds for novel PD therapies."

PDF Executive Director, Robin Anthony Elliott, said of the grants, "Our board of directors and my colleagues at PDF were deeply affected by how the loss of one family foundation and its millions of dollars of support can have such a direct and catastrophic effect upon PD research"

These grants are part of PDF's four-pronged approach to funding Parkinson science. PDF's research initiatives include a Center Grants Program, which funds research at three leading universities; the International Research Grants Program, which provides seed grants to promising scientists studying the science of PD; career development and fellowship programs that support continued interest in the field of PD; and collaborative endeavors with other organizations that fund PD research. In fiscal year 2009, PDF will contribute \$5.4 million to support PD research.

INTERVIEW-SOLVAY PHARMA CEO HOPES FOR PREDICTABLE FDA

By Bill Berkrot 02.27.09

- CEO sees Solvay PD treatment in U.S. in 2011
- Says could be worth hundreds of millions of dollars
- Says hoping for more predictable FDA

NEW YORK (Reuters)—At the behest of U.S. regulators, Solvay Pharmaceuticals is busy testing a treatment for advanced PD that has been available in Europe for 10 years. *That means Americans who could enjoy a dramatically better quality of life will still have to wait at least two more years for the therapy.* [our emphasis—stan] "It's the difference between the patient being in a wheelchair or walking," Werner Caultreels, chief executive of Solvay Pharmaceuticals, said in an interview on Friday.

The company is hoping new FDA leadership will prove more predictable than its predecessors after a decade of real world safety and efficacy information from European patients was not enough to satisfy the agency. "Unfortunately they asked us to do a few more trials, which we have running," said Caultreels.

Based on current progress in two 54-patient Phase III trials, Caultreels expects the treatment likely will not be available to U.S. PD patients before early 2011. Caultreels expressed frustration at having to conduct

placebo-controlled studies, which means about half the patients in the trials are not getting the therapy. "It is going to be tough to maintain at trial when investigators see the difference," Caultreels said.

Patients with an advanced form of [PD] experience unpredictable fluctuations in mobility and motor control that gets progressively worse with time. The treatment, levodopa/carbidopa intestinal gel, is a form of long used oral medications that lose effectiveness as the disease progresses. Researchers at Sweden's Uppsala University discovered that the drugs delivered directly to the intestines through a catheter continued to help with motor function long after the oral formulation stopped. "The only option late stage patients have is deep brain stimulation. This would be the alternative to that," Caultreels said. The treatment could be worth "some hundreds of million dollars" annually to Solvay, Caultreels said. He doubts it will reach \$1 billion blockbuster status. "The patient would have to accept carrying a pump around and a little surgery" to implant the catheter, Caultreels explained.

http://www.forbes.com/feeds/reuters/2009/02/27/2009-02-27T215150Z_01_N27357779_RTRIDST_0_SOLVAY-INTERVIEW_print.html

Comment: This article raised my hackles: we seem to be behind the rest of the world in pharmaceuticals generally (Mirapex was first accepted in Europe), Deep Brain Stimulation (Swedish/French project—many years before us), Miralax (at least five years before us), and so on. In this case, a procedure with a workhorse drug (Sinemet) has been successfully and safely used in Europe for TEN years but the FDA makes the manufacturer go through hoops which will delay the procedure from getting to the people who need it by three to four years. This is clearly NOT a thalidomide mess-up. Unless I hear evidence to the contrary, I believe Solvay should be able to market its drug delivery procedure immediately. If you agree, let's talk about what we can do to make it happen.

JOURNAL OF THE AMERICAN CHEMICAL SOCIETY ON MAR 7TH, 2009
UNDER: HERBAL REMEDIES by Kathleen Blanchard RN

Turmeric has been used in India for its powerful medicinal properties for centuries. A new study shows that it has powerful healing powers. The cancer and infection fighting ability of turmeric was found by University of Michigan researchers by using a special technique that allowed scientists to watch how turmeric has earned the name "holy powder" in India. Curcumin (CC), the main ingredient in turmeric, fights infection and promotes good health by entering blood cells, to keep things orderly. The findings could lead to powerful compounds that can be used to fight disease. "The membrane goes from being crazy and floppy to being more disciplined and ordered, so that information flow through it can be controlled," says the study author.

NOTE: There has been much discussion about alpha synuclein recently as a possible cause for PD; it has to do with impeding debris cleanup at the membrane of the nucleus of the cell—hmmmmm. Stan

The Michigan research team, led by Ayyalusamy Ramamoorthy, observed how CC in turmeric behaves inside the cell membrane, using solid-state NMR spectroscopy. The special technique allowed the researchers to watch how CC changes the structure of the cell membrane. The result of the disciplinarian type action exhibited by CC in turmeric improves the function of the cell membrane, increasing the body's resistance to cancer and infection. Turmeric exerts its healthy influence on cell membranes indirectly, contrary to the more commonly held belief that turmeric has a direct effect on cell membranes.

The research group is exploring other ways that CC might help fight diseases like PD, with the same special technique his team used to find how turmeric keeps cells membranes orderly.

NOTE: Another in a growing list of natural remedies, as opposed to exorbitantly priced manufactured ones that originally came from the natural.

ESSENTIAL TREMOR AND PARKINSON'S DISEASE

By Jared Tanner, MS, (*NEUROSCIENCE & NEUROLOGY*)

March 07, 2009 Parkinson's disease (PD) and essential tremor (ET) are both primarily movement disorders. The symptoms are commonly confused with each other, mainly because ET is not as well known as PD even though ET is more prevalent. High-profile people like Michael J. Fox and Muhammad Ali raised our awareness of PD in the 1990s just like Pres. Ronald Reagan did with Alzheimer's disease in the 1980s.

The two disorders differ in etiology and symptoms. Scientists understand the cause of PD quite well. It manifests when there is a loss of about 80% of the dopamine-producing neurons in the substantia nigra, a small area within the brainstem. However, we do not know what causes the death of these dopamine-producing cells. The etiology of ET is not understood as well. What we do know is that the mechanics of ET, like PD, involve the deep nuclei and white matter of the brain, including the thalamus and striatum.

The symptoms of PD include tremor, rigidity, akinesia, and postural instability. Bradykinesia (slowed movements) and bradyphrenia (slowed cognition) are also common symptoms. If tremor is present in PD (it does not have to be), it is manifest mainly as a resting

tremor. However, when someone with PD moves and tries to do something, the tremor usually goes away. In other words, there is less of an action tremor than a resting tremor. Emotional changes are also common; depression and facial masking (little facial expression of emotion) are particularly prevalent. With ET it is more common to have just an action (or intention) tremor and a postural tremor. Both diseases are progressive (although some forms of ET do not progress). Both diseases can be very debilitating. Patients with ET are more likely to develop or have PD.

Treatment of PD usually starts with levodopa, a precursor molecule the body can turn into dopamine. Treatment of ET usually involves taking various pharmaceuticals, including beta-blockers or anti-seizure medications. Deep brain stimulation (DBS) of the subthalamic nucleus, globus pallidus, or thalamus are becoming more common treatments of both ET and PD. DBS was approved for treatment of ET in 1997 and for PD in 2002. While we still have a lot to learn about these two diseases, we have come a long way in understanding and treating them.

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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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