

Connecticut Parkinson's Working Group Newsletter

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RECENT GIFTS TO CPWG

This space will contain acknowledgement of gifts to the CPWG and, if specified, who the gift honors. It will appear even if there are no gifts to report.

We gratefully acknowledge a generous gift in memory of Brenda M. Yates made by Karen Archambault, Brenda M. Keane, Frank Guzzardi, Shari LeBel, Nancy Poust, Sergio Heiber, Karen Kee, Clairissa Dawson, Loretto Cavallari, Gwendolyn Douglas, Sandra Silva, Kristi Rice Lorie Tringalli, Joseph Pristritto, and Raymond Lozefski.

We have had several articles on alternative treatments; this is another. I believe that although most of us follow a traditional western medicine approach toward treating PD we are also open to other modalities; indeed, many are deeply involved with at least one alternative approach in conjunction with the standard. That seems like a healthy attitude to me. — *Stan*

CERVICAL CHIROPRACTIC CARE CLAIMS

A chiropractor in Boulder, Colorado, Erin Elster, D.C., has written an article for the Journal of Vertebral Subluxation Research (2 Aug 2004) in which she calls for more and more structured research into the role of head and neck trauma in MS and PD. She presents some personal work done over a period of five years suggesting a strong connection. From the article:

Eighty-One Patients with Multiple Sclerosis and Parkinson's Disease Undergoing Upper Cervical Chiropractic Care to Correct Vertebral Subluxation: A Retrospective Analysis

Erin L. Elster, D.C.

ABSTRACT

OBJECTIVE: The objective of this article is threefold: to examine the role of head and neck trauma as a contributing factor to the onset of Multiple Sclerosis (MS) and Parkinson's disease (PD); to explore the diagnosis and treatment of trauma-induced injury to the upper cervical spine through the use of protocol developed by the International Upper Cervical Chiropractic Association (IUCCA); and to investigate the potential for improving and arresting MS and PD through the correction of trauma induced upper cervical injury. Data from 81 MS and PD patients who recalled prior trauma, presented with upper cervical injuries, and received care according to the above protocol are reviewed.

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CLINICAL FEATURES: Each patient was examined and cared for in the author's private practice in an uncontrolled, non-randomized environment over a five-year period. Of the 81 MS and PD patients, 78 recalled that they had experienced at least one head or neck trauma prior to the onset of the disease. In order of frequency, patients reported that they were involved in auto accidents (39 patients); sporting accidents, such as skiing, horseback riding, cycling, and football (29 patients); or falls on icy sidewalks or down stairs (16 patients). The duration between the traumatic event and disease onset varied from two months to 30 years.

INTERVENTION AND OUTCOME: Two diagnostic tests, paraspin digital infrared imaging and laser-aligned radiography, were performed according to IUCCA protocol. These tests objectively identify trauma-induced upper cervical subluxations (misalignment of the upper cervical spine from the neural canal) and resulting neuropathophysiology. Upper cervical subluxations were found in all 81 cases. After administering treatment to correct their upper cervical injuries, 40 of 44 (91%) MS cases and 34 of 37 (92%)

PD cases showed symptomatic improvement and no further disease progression during the care period.

CONCLUSION: A causal link between trauma-induced upper cervical injury and disease onset for both MS and PD appears to exist. Correcting the injury to the upper cervical spine through the use of IUCCA protocol may arrest and reverse the progression of both MS and PD. Further study in a controlled, experimental environment with a larger sample size is recommended.

N.B. (editorial comment) She clearly states that her experiment was uncontrolled and she had a relatively small sample. There is no mention of the placebo effect or the effect of simply participating in a study, which can cause people to have surprising outcomes with no real treatment; Ms. Elster is clearly aware that there are these and other objections to her dramatic results. However, there surely seems to be enough here to carry on the extended research she wants. If you want to explore the entire article, go to the web site .

<http://www.erinelster.com/>

JEFF LINCOLN INTERVIEW WITH DANNA JENNINGS, MD, JULY 13, 2004.

J—What I usually ask folks when I start out is: When were you diagnosed, what medicines are you on and what are your main symptoms? None of this applies to you at all. The reason we're doing this interview is that I do a series of interviews for the Connecticut Parkinson's Working Group (CPWG) Newsletter. Although you don't have Parkinson's Disease (PD), people are interested in your thoughts.

The question that I wanted to ask you is, how did you get to where you are? Did you start out to be a Neurologist right at the beginning of Medical School?

D—No, let me tell you how I got to be interested in Neurology in the first place. I was in nursing school. I was working on the neurology - neurosurgery floor in a hospital. I became incredibly interested in the neurology patients. And so at that point I decided I wanted to do more than just take care of patients from a nursing point of view. I wanted to be prescribing the medicines and understanding the diagnosis and testing. I decided to apply to medical school after I completed nursing school. So I applied for medical school while

I was working as a nurse, and I got in.

J—Where did you go?

D—Oregon Health Sciences. I continued working as a nurse while I was in medical school. So I was seeing things as I was learning things. When I got to neuroanatomy, I got especially excited, because I was seeing actual neurology patients while learning neuroanatomy, and it all seemed to come together for me. Once I got far enough in medical school, I didn't have time to work because I was on the ward as a medical student seeing patients. And so I ended up not working as a nurse that point, and that's when I started thinking what am I going to do? Am I going to be an internist? No, you have to know too much about too many things. I want to be more specialized. I had a big decision between neurology and psychiatry. I couldn't make a decision. As a matter of fact, I applied for residencies in both. And then I went on the interviews for both neurology and psychiatry. I decided after meeting some of the psychiatrists that I felt better thinking of neurologists as my colleagues. So ended up doing neurology. As

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I got in neurology, I realized that there is a ton of psychiatry in neurology. There is a lot of overlap between neurology and psychiatry.

J—Where did you take your residency?

D—I moved to Boston from Oregon(which is culture shock) and I did my residency at Boston University with Dr__ who was really interested in PD. He had a very large PD practice and the team at the new England Department of Neurology had three to four movement disorder specialists at any one time. So I was exposed a great deal to PD. That's when I became interested in PD. I have to tell you that as a medical student at Oregon health sciences, I was in a lecture given by somebody who is a PD specialist, Dr__. He actually brought a patient to the lecture. The patient had not taken medicines before the lecture. His movements were slow, his posture was stooped, his speech was soft, he was really off. At the beginning he examined him in front of the class, and you could see what he looked like before the medicines. Then he gave him Sinemet. He proceeded to give his lecture. He then examined him at the end of the lecture an hour later. You could see a tremendous difference in his ability to move, and it was so clear to me that of all the neurological conditions that people with PD actually get better with the medicines. They make people feel better. I found it a bit more rewarding than the other areas of neurology. That was my first exposure to PD. And then as a resident I became very interested in PD. I had a ton of exposure and a very good set of mentors at Boston University. It was terrific. I'm still in contact with them.

J—How did you make the connection with the Institute for Neurodegenerative Disorders (IND)? Actually, at the time it would have been the Yale Movement Disorder clinic

D—I ended up doing a Fellowship. After a Neurology residency, if you want to specialize in something, you have to do a fellowship. I looked around (I wanted to stay in the North East). I went to New York to do fellowship with Dr__ at Columbia Presbyterian. I was one of his fellows for two years. After that, I wasn't sure what I was going to do. Did I want to go into private practice? It was a big decision whether to go into private practice or into an academic setting. I interviewed at several private practices and Universities. And then I met Ken Marek who was at Yale. We spent a lot of time together and I decided to take the

job he offered. That's how I got to Yale.

J—How did you get to IND?

D—I was at Yale for almost 4 years. Ken made the decision to leave Yale and he offered for me to come with him. I said yes. That's how it all started at IND. As you probably know, a lot of the people who were at Yale also were interested in keeping the group together.

J—So that brings you up to today. I gather that Research is the main thing.

D—Yes, research is our main objective.

J—And what is your title at IND?

D—Clinical Research Director.

J—Do you actually decide which studies to do?

D—Sometimes I decide but most of the time we decide as a group. We learn about studies in different ways, and we meet every week to discuss new studies and the progress of current studies. We decide as a group what studies are important to put our focus on and where to put our resources. We turn down a number of studies because they are not well designed and won't answer the question at hand.

J—Do you turn down more studies than you accept?

D—I'm not sure that's true. It might be 50-50.

J—When you are first diagnosed, lots of things cross your mind. Do you have any advice for people newly with PD?

D—Take time to really digest what's happening. Do some reading. Think about what this is going to mean to you. It takes time and there's no substitute for time. It takes months to years to adjust to the new diagnosis. During this time, it is not necessary to make quick decisions. Many times the PWP doesn't need to take any medicines. Some PWPs feel they have to take something right away. I think it's better to just wait. It has taken a long time for the disease to reach this point.

The other thing is to just keep going. Keep working as long as possible. Travel as long as possible. Do exercises, plan an exercise program. It's easier to start when you're diagnosed than to pick it up later when it's an uphill battle.

J—when I was diagnosed, I went into denial.

D—Denial is not a bad thing. If you are doing everything that needs to be done, denial allows

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you to keep going.

J—Anything you would like to add before we close?

D—The most important thing is for people to be hopeful. There are so many things that are in the pipeline or on the horizon to give a sense of hope to people. And we're right in the thick of it.

J—Thank you for spending the time me and for your insightful comments.

{And thank you from the recipients of the newsletter too—this was a superb interview. Terry Gross watch out!!}

Gunilla Norris's New Book is Now Available.

INVITING SILENCE: Universal Principles of Meditation, published by BlueBridge in paper, \$12.95, has come out to complimentary reviews. Publisher's Weekly says, "A writer, therapist and meditation teacher, Norris pens an invitation and a challenge: be still. She writes for those who begin to experience spiritual yearning . . ." They go on to write, "her instructions on beginning to meditate . . . are simple and gradual. The material is logically organized, covering in friendly and flowing language what a beginner needs to know." Later on: "A published poet, Norris chooses an evocative form for her words, a kind of spiritual blank verse . . ." and; "This small, gift-sized book successfully gives a gentle nudge toward a demanding spiritual discipline."

This is the kind of publication that many of us need; it presents an activity that would be of clear benefit at a level that is attainable and sustainable.

maintain their independence," she says.

"It's important to look at each individual," stresses Tim Kauffman, PT, PhD, professor of physical therapy at the Hahnemann campus of Drexel University in Philadelphia. "Every person of any age has an individual background, say an auto accident, football injury, genetic predispositions. No two 'old' people are the same." According to APTA, physical therapy can restore or increase strength, range of motion, flexibility, coordination, and endurance—as well as reduce pain. Another important role is to retrain the patient to do everyday tasks.

Guy Davidson, of Tempe, Ariz., was 70 when he had a stroke following bypass surgery. The formerly busy minister could not speak, his right leg would not support him, and his right arm hung straight down. He went into rehab for three months. At first he could only sing, which uses a different portion of the brain than speaking, but gradually he began to speak. After many stressful sessions ("I would be sweating," he admits), he regained much use of both his arm and leg and can dress himself, drive (he took lessons), and work full time. Now he's back in the hospital every day—visiting sick parishioners.

This next article is not devoted to PD; however, it has a lot for any PWP who wants to care for her/him self.

PHYSICAL THERAPY A BOON FOR SENIORS

Would you believe in a nondrug treatment that works for arthritis, cancer pain, Parkinson's, and incontinence and improves your strength and endurance? There is one—physical therapy.

By Star Lawrence, WebMD Feature Archive Reviewed By Brunilda Nazario, MD

When a person gets injured or has a prolonged illness, doctors often recommend physical therapy. In the case of older people, though, sometimes this is seen as just something to “try.” This could not be further from the truth. Physical therapy is “Aquality” therapy for many conditions affecting older people, from Alzheimer’s to urinary incontinence. In fact, one researcher did a study in which you had to be 100 years of age to even participate! According to Jennifer M. Bottomley, PhD, MS, PT, president of the geriatrics section of the American Physical Therapy Association (APTA) and adviser to the surgeon general, one of the main things that brings older people to the physical therapist is a fall. “They want and need to

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Conditions Helped by Therapy

Physical therapy referrals are appropriate and helpful for many problems thought of as affecting older people. Take arthritis, for example. By 65, almost everyone has it in their spine, Kauffman says, though not everyone has symptoms. Besides taking a pill, sufferers can avail themselves of many types of physical therapy—aquatic, hot packs, electrical stimulation, ice to reduce swelling, there is a long list. “We emphasize strength, range of motion, balance, and coordination,” Kauffman says. “We get a lot of referrals for osteoporosis,” Bottomley notes. “We try to make people more stable in relation to gravity, doing extension exercises to keep posture erect. Osteoporosis can lead to falls and bones can be injured.” (Weight-bearing exercise earlier in life can also prevent osteoporosis, studies show.)

Physical therapy can also help alleviate some of the pain associated with cancer. “We want to maintain the highest functionality,” Bottomley says. “The correct exercises after mastectomy can reduce swelling and improve range of motion,” Kauffman says. “The therapist has to determine the right exercise and right amount based on clinical judgment (rather than patients just moving around as much as they can stand to at home).”

How about that old favorite, incontinence? “This is an exercise in locating the muscles that control that and operating them at will,” Kauffman says. Social timing is also important—knowing how soon after drinking something you will need to use the restroom and planning for that. A physical therapist can help establish such patterns.

More Conditions

Strokes, as Davidson’s experience illustrates, definitely require physical therapy. “We use something called proprioceptive neuromuscular facilitation,” Bottomley says, explaining that this is a purposeful movement pattern that can stimulate and retrain the brain. Another technique—which Davidson says greatly helped him—is constraint therapy, in which the stroke sufferer’s “good” limb is restrained and the weak or paralyzed one used 85% of the day. Speech retraining also can be an issue. “If the person is in pain, we can treat that electrically,” Kauffman says. Parkinson’s is an “exciting” area, Kauffman says. “We have learned that physical intervention early—before stage 4, when the therapist is often

summoned—can almost always prevent the severe symptoms of stage 4.” He explains that the goal is to keep the Parkinson’s patient’s trunk flexible to avoid “robotic” movements. (Parkinson’s disease is a chronic disease of the nervous system that results in a gradual decrease of muscle control.) Sometimes he has people lie on the floor and move their head and trunk in opposite directions. He even puts patients on horseback sometimes, which increases trunk strength and flexibility.

Balance is another issue with older people. “Balance is very complicated,” Kauffman says. “It requires many systems in the body—nutrition, oxygenation of blood, muscle strength, joint receptors, vision, inner ear. Physical therapy can tune up all of these areas. In one case, peripheral vision, patients are asked to throw and catch a weighted beachball that curves and wobbles through the air unpredictably, like a knuckleball.

Therapy is almost always prescribed for hip fracture and replacement patients, amputees, and those with joint aches and pains. “I call the latter ‘grandparenting injuries,’” smiles Bottomley. “The grandkids come over and the grandparents take extra walks or climb on the playground equipment. Come Monday morning, ouch.”

Role of Family

Even though an older person may have had a hospital stay or required extra attention, family members should be positive and supportive of more trips—this time to therapy, Kauffman says. Relatives also need to understand the loss of mobility and independence. “It was a frightening experience to go home and be dependent,” Davidson says. “They put up some grab bars, but I could not do things for myself.”

Kauffman urges that family members never be dictatorial or expect a certain level of progress. Davidson adds, however, that you should find a therapist with goals and not one who is letting the insurance run out “hoping” you will improve. Families should participate rather than nag, according to Bottomley. “When you come over, say, ‘Mom, are you up to a walk?’” It is also important to be sure the patient is eating correctly— bring microwaveable meals, or else your loved one may be living on crackers and cheese.

Above all, physical therapy is an ongoing process—a journey. And as with all journeys, there will be ups and downs. Realistic expectations and

a sense of humor help. In one case, a stroke victim had a little trouble with splatters in the bathroom, so he threw water all over his pants and came out warning others about the rogue faucet that had drenched him.

Star Lawrence is a medical journalist based in the Phoenix area.

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<http://my.webmd.com/content/Article/58/66563.htm>

This is an email I recently received from a distant member (Diana Lee—Florida) of CPWG—once a member always a member. It was of sufficient interest to pass on. I hope it reminds everyone that we really do thrive on connecting with each other.

Hi Stan:

Outside of expecting my third hurricane—taping windows, filling bathtubs, getting food and gas etc.— things are going along well. I am now taking glutathione three times/wk alternating with twice the following week (COST!!! it is expensive) . I do think it is helpful. I am only on one dose of amantadine per day—100mg—and lots of magnesium (Dr. P[erlmutter] is a big believer in magnesium tabs to relieve cramping etc. It seems to work.) What I recommend is that you look at his three Tier diet in the back of his new book *The Better Brain Book*. I am trying to take the vitamins suggested.

I miss the Working Group—it really is a great group—so I look forward to the newsletters. I did email the person who would send it online but have not heard back on that. If it would save \$\$ I would be happy to get it that way. Good luck with everything and I will try to keep you abreast of new developments here.

I had a call from my manager at Coldwell Banker. It seems that the sister of J. Estes—wrote book on ALS before she died—is a CB agent and CB corporate has decided to support the ALS foundation that her 2 sisters have started. I saw them interviewed on TODAY. I told my manager I was delighted to hear that because I think the research they do will also benefit PD. He had me go on his voice mail to our office of 50+ agents to encourage support. I was glad to do it and have had a good reaction. Bye...DIANA :-)

PARKINSON'S DISEASE CELL LOSS STARTS YEARS BEFORE DIAGNOSIS

28 Apr 2004

The loss of brain cells that leads to PD starts an estimated 13 years before the diagnosis, according to research that will be presented at the American Academy of Neurology 56th Annual Meeting in San Francisco, Calif., April 24–May 1, 2004.

The study examined the brains of 12 deceased men who had PD and compared them to the brains of 174 men who were of similar ages when they died and did not have PD. The researchers counted the number of neurons, or brain cells, in a section of the substantia nigra area of the

brain. PD is caused *[this is not really true. Many of the symptoms of PD are a result of loss of nigral cells. Stan]*

by the gradual loss of cells in the substantia nigra. The average number of cells was significantly lower in the men with PD than in the other men. Furthermore, the longer the duration of PD, the lower the neuron count.

At the time of diagnosis, it was estimated that the men with PD had, on average, 40 percent fewer neurons than those without PD. With further analysis, the researchers estimated that the loss of neurons starts about 13 years before the diagnosis is made.

“If people destined to develop PD could be identified during this pre-clinical window, then theoretically it should be possible to intervene with some treatment to prevent the symptoms of PD from developing fully,” said study author and neurologist G. Webster Ross, MD, of the Honolulu

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Department of Veterans Affairs in Hawaii. “We need to continue to look hard for biomarkers of PD that would help identify people with the disease before they develop the symptoms.” The study was supported by the NIH, the

National Institute of Neurological Disorders and Stroke, the National Institute on Aging, the Department of Veterans Affairs and the U.S. Department of the Army.
From the Michael J. Fox web page.

This is a note transmitted by Steve Holahan, our treasurer and grants person. It is a great opportunity for anyone who needs a computer whose intended use is for any task involving CPWG, which may be only sending and receiving email between members. They are very free when it comes to utilization, so . . .

FYI: CHEAP REFURBISHED COMPUTERS FOR NONPROFITS

Hi Everyone, An FYI to groups looking for high quality, steeply discounted computers: Geeks for Givers, a nonprofit organization based in Chester, “rescues” high-end corporate computers destined for landfills, refurbishes them, and resells them to nonprofits at a VERY low cost. Once rescued, Geeks wipes out hard drives and installs fully licensed Microsoft operating systems, firewalls, Winzip and BasicFunder (a simple nonprofit donor/membership database). By the time groups get their “new” computers, all they have to do is load their software. (Or if you are a techno plebe like me, give them your software and they’ll load it for you.)

Geeks also services groups in Massachusetts and Rhode Island on a limited basis. Costs per computer are determined according to 1) your organization’s operating budget and 2) the type of system your group wants, i.e., a Windows 98 system (\$60-\$80), a Windows 2000 system (\$80-\$100), or a laptop (\$110-\$130).

For more information, visit the Geeks for Givers website (www.geeksforgivers.org). You can contact them directly at (860) 995-5330 or at info@geeksforgivers.org.
All my best, Kim Collier Executive Director

JIM WEST AWARDED EMMY

Jim West has had a long and successful international career in the music world as a vocalist in Las Vegas, a jazz bass player, audio producer in Dallas as well as other centers in the USA and in other countries, and in voice-over. His voice-over career started as a side-bar to his production and marketing efforts but quickly out-distanced all of his other activities.

As a result, Jim expanded his voice-over career and his “Jim West—America’s Story-teller” voice. It is heard on leading commercials for Tony Roma Ribs, IHOP, Blue Diamond Almonds, McDonald’s, Armour’s, and dozens of other well-known companies. His voice was the singular sound of the two Ross Perot Presidential campaigns in ‘92 & ‘96.

He lives in Weston, Ct, continuing his work narrating films and doing charitable work helping children’s orphanages in Russia, Romania and China. He also enjoys the antics of three highly energized grandsons.

Jim was recently awarded an Emmy for his narration of a series of children’s stories, Disney’s *Legends of the Ring of Fire*. Read more about this and Jim in an upcoming newsletter when he is interviewed by Jeff Lincoln.

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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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