



CONNECTICUT PARKINSON'S WORKING GROUP News

CHANGING PARTNERS!

SPRING 2011

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By Debbie Weinstein

Since the last issue of this Newsletter, the Dancing with Parkinson's classes, initiated by CPWG in New London and Middletown, have acquired a new owner and management. Jackie Dorwin, president of CPWG, turned over the reins, along with a check for \$9000, to The Neighborhood Music School (NMS) of New Haven. NMS was already operating a similar class and was the natural organization to carry the program forward. I caught up with Arri Sendzimir, Director of Special Projects for NMS, by phone during her busy schedule to get some background on the school and their plans for the PD dance program.

She explained that the Neighborhood Music School was established in 1912 in New Haven "as part of the Settlement House movement, offering music classes to residents of the city. Today, the organization offers music, dance, and theater classes and performance opportunities to almost 3000 students from all over Connecticut, thanks to 130 professional faculty members." She went on to add that "in spite of the name, NMS is more a community than a school. Its arts-based Preschool operates all day, five days a week; adults come for classes primarily in the mornings; and school-age students fill the halls in late afternoon, early evening, and weekends."

Changing demographics led them to offer more adult activities, which resulted in the highly successful Vintage Voices class for persons over 50 who wish to sing and dance as a group. The Dancing with Parkinson's class met the same criteria and a New Haven class was formed. They quickly realized that there were advantages to having classes in multiple lo-

cations and, therefore, acquiring the two established classes from CPWG was a natural progression. In fact, Arri informed me that they are working with several other PD support groups around the State to see if there is interest in forming more classes. The only requirement is that the group be able to provide free space for the class—NMS will supply the instructors.



Arri Sendzimir & Jackie Dorwin

Arri conveys a wonderful enthusiasm for the program and although she admits that Dancing with Parkinson's classes have proven to be challenging, they have also been inspiring. "The teaching faculty requires specialized training, and participants have travel restrictions that can prove daunting." However, she also points out that there is "great excitement within the school for this program" and definitely leaves one with the impression that the two former CPWG classes are in very good hands!

[The "Dancing with Parkinson's" program is managed by Arri Sendzimir, Director of Special Projects at Neighborhood Music School, who can be reached at (203) 624-5189, extension 15. She encourages you to call if you have an idea or a suggestion]

EDITORIAL

LETTERS TO THE EDITOR:

Judith Iovanna writes to us with the following humorous account of her experiences as a PWP.

The Devil's in the Doorway!

DOORS, DOORS!! What is it about doors and Parkinson's disease? For me, they represent obstacles that need to be avoided. Let me share a few of my door experiences with you. My first doorway encounter happened as I was leaving an office supply store. I was feeling great. I left the checkout counter and headed toward the exit doors. Fortunately, they opened electronically and I passed easily through the first set of doors. My thought was, "Feeling good, just keep going." Suddenly, as I approached the second set of doors, I froze! My feet became one with the floor. I could not move. What's happening, I asked myself? Don't panic, I thought, try to relax and breathe. I noticed a customer approaching the doors and I pretended to be looking for my car keys. I jiggled my purse, fished around in my coat pockets, and even looked on the floor. I rummaged through my pockets again in a futile attempt to make it look as if I could not find my car keys. I was hoping I could trick my body into moving. My mind was swirling. As a customer walked up to the doors to leave, he saw me struggling and asked if I was okay. "Just fine, thank you," I chirped. He proceeded to the exit doors. They easily opened for him and he was out in the parking lot. Okay, I can do the same, but each attempt I made to move proved useless. I was beginning to panic. Miraculously, an employee of the store came out and gently said, "Let me help". She held my arm and I crossed over the threshold and through the exit doors into freedom. Now that was easy!!

But there was a next time. My visit to the library was supposed to be a fun event. I approached the front entrance where there was an electronically operated door, a "gift for PWP". All I had to do was pace myself and adjust my walking so I could casually walk through the doorway without any fanfare. Just as I approached the door, much to my dismay, as the door began to open I noticed it was beginning to fold in half during the opening process. Horror of horrors! I did not expect this – whoever saw a door fold? And it folded with me in it! I was not quick enough to escape the door. I was trapped in the fold!! "I don't believe this is happening", I muttered to myself. Here I am trapped in a folding door in the public library. A newspaper headline flashed before my eyes. "Local Woman Gets Stuck in Fold of Library Door! It took firemen several attempts to extricate her from the fold. Woman plans to use non-electric side door in the future."

It took me at least a minute to pry myself out of the fold and enter the library. When I finally emerged from the fold, I noticed some patrons standing by the check-out desk with looks of wonderment and amazement. I said nothing – some situations need no explaining!

My most memorable experience with doors happened recently. I was traveling on a highway and needed to use a public restroom. As I entered the room, there were several stalls. I decided to use the first unoccupied stall. As I grabbed the door handle and pulled, I realized that the door was stuck. So I put both hands on top of the door and pulled as hard as I could to open it. As soon as I did this, I felt myself begin to lose my balance. Then it happened! In my attempt to stay upright and prevent falling on the floor of this busy restroom, I was out of balance. I clung to the door with both hands. This caused me to swing in and out of the stall while hanging onto the door. I knew if I could not balance myself, the fall was inevitable, so I continued to swing. After about the fourth swing, I steadied myself enough to put one foot down firmly on the floor and then the other. I was finally able to get off this merry-go-round. I composed myself, being grateful that I avoided an accident. As I began to enter the stall, I looked around to see if anyone was watching. Yes, there she was, mouth opened, standing in disbelief with what she just witnessed. I greeted her with "Great doors aren't they!!" You just have to laugh.

Mouse Madness

When describing my Parkinson's disease to other people I will frequently say, "My body has a mind of its own." Lately I have been feeling that way about my computer. Put the computer in the vicinity of my body and there is no telling what will happen. Which brings me to my question for your readers: How do they control the mouse when tremors are active and cause major delays in work. Any recommendations?

Thank you for your help and advice.

*Jackie Dorwin
Guilford CT*

We would like to hear from you

Send your questions, comments, or observations online to debbie.weinstein@cpwg.org.

BOOK REVIEW—BY KENDRA HOUGH

SHATTER by Michael Robotham

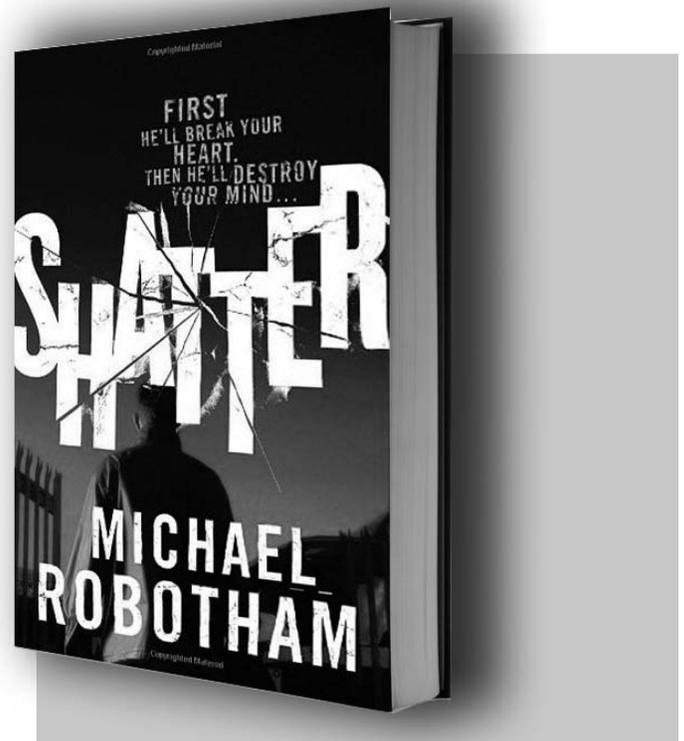
What is a PWP doing in a fast-paced, high tension psychological thriller? Aussie author Michael Robotham tells me that he did not want a “James Bond” hero who could “out-fight, out-run, and out-womanize every villain”. He wanted someone clever ... “with a brilliant mind, but a crumbling body”. His choice of psychologist Joe O’Loughlin to oppose a disturbed and manipulative, highly trained member of the military makes for an all-night read that just cannot be put down. Author Robotham has a sharp interest in irony.

I cannot bring myself to outline the plot, as I do not want to spoil your own enjoyment of this novel. I will give you some hints! Elements of family life and childrearing are important to this story. Fidelity in the face of Parkinson’s is an issue. Interrogating techniques bordering on torture certainly show their ugly face. High technology is an essential thread. Revenge is in the mainstream. Graphic description is present but not overdone. Mystery underlies the question of how a killer can kill without approaching his victim?

*He wanted someone clever ...
“with a brilliant mind, but a
crumbling body”.*

Robotham includes enough juicy bits to grab your interest immediately. His setting of England provides the right amount of backdrop to hook the Anglophiles without getting caught up in the cute English village phenomenon. This book provides enough intrigue to appeal to the intellectual without losing him to the confusing technique of flash-backs, so often employed by authors of similar genre. His choice of a psychologist as counterpoint to the rigid, fact-based police investigation brings credibility to the scene, as it reveals the basic human instincts of love and the desire to protect one’s family from harm. I would bet that we, more than other readers, feel Joe’s tremor, flinch as he stumbles, recognize his paranoia, relate to his doubts, know his panic, empathize with his need for reassurance and love, and understand his fear of abandonment.

I will leave you intrigued with two quotes from the book. The hero says about the villain: “Any sign of weakness is preyed upon. He can recognize a flagging heart, distinguish inner strength from a charade and find the fault lines in a psyche. He tears minds apart. I try to repair them.” and “The world is full of broken people and most of their cracks are on the inside.”



I give Robotham my highest accolade ... that is to say, I think I will read this book again.

About the author:

Michael Robotham is a respected Australian writer of varied experience. From newspaper journalism to ghost-writing the histories of famous persons to developing his own crime thriller series starring Joe O’Loughlin, Mr. Robotham delivers substance in the areas of education and entertainment. It is our pure luck that although he had no intention of creating a series, Joe O’Loughlin has been a strong enough character to appear in his other novels. One copy of this book is being donated to the CPWG library for your enjoyment, by K. Hough

[Ed. Note: Kendra wrote to Michael Robotham and received a very nice reply, explaining his choice of a PWP as his hero, as noted early in her review. But he also indicates that he has “done quite a bit of research into PD.” He acknowledges that every case is different and that he has “glossed over elements of the side-effects, etc.” but he has tried “to be as honest as possible.” He goes on to say that he has had contact with many PD groups “whose sense of humor and stoicism is remarkable. Most really appreciate that I have a hero with PD, who is helping educate as well as entertaining readers”.]

MEDICAL UPDATES

With this issue of the Newsletter, we introduce a new format for reporting on Clinical Trials and new Treatments for PD. It was designed by CPWG Board Member, Tess Deshefy-Longhi, DNSc, RN, whose background in research and whose personal connections to PD brought her to the realization that our role should be to report these items with accuracy, brevity, and transparency. Her framework lays out the purpose of the trial, the phase that it is in, the source of the information and where it is reported, the findings of the study, and whether there are any further trials scheduled. We hope that this method will provide our PD community with enough detail to keep abreast of the research scene and at the same time allow us to make intelligent assessments of the data. We will, at times, provide definitions of terms (indicated by an *) for a better understanding of the report.

DRUG TRIAL: Drug ADX48621—to reduce Parkinson Disease Levodopa-Induced Dyskinesias or PD-LID

Trial/ Study Purpose: These are initial findings from pre-clinical trials (i.e. animal trials) regarding the efficacy* of Addex Pharmaceutical's drug ADX48621 in reducing PD-LID.

Clinical Trial Phases completed: Pre-clinical animal trials with the rat model. Pre-clinical animal trials with the MPTP monkey model of PD-LID

Trial Information Source: Addex Pharmaceutical Company

Reported in: *Medical News Today*, June 2010 issue

Findings: Pre-clinical animal trials with the rat model indicated that efficacy increased as the dosage increased, with a reported 65% decrease in catalepsy (muscular rigidity) time at a dose of 30 mg/kg.

In the MPTP monkey model of PD-LID, this same dose (30 mg/kg) of ADX48621 resulted in "statistically and significantly inhibited PD-LID".

Mode of action for ADX48621 appears to reduce excessive glutamate stimulation in the striatal pathway that is associated with PD-LID.

Next Clinical Trial Phase: Clinical Phase I trials of ADX48621 with selected people with either PD-LID or

with dystonias* are slated to start near the end of 2011 according to Addex.

***Efficacy**—the maximum ability of a drug or treatment to produce a result regardless of dosage. Drug or treatment passes efficacy trials if it is effective at the dose tested and against the illness for which it is prescribed. Phase II trials gauge efficacy, Phase III confirm it.

***Dystonia**—a neurological movement disorder, in which sustained muscle contractions cause twisting and repetitive movements or abnormal postures.

DRUG TRIAL: Randomized, Double-Blind Study of Gene Therapy for PD (AAV2-GAD)

Trial/ Study Purpose: This was a randomized, double-blind study* that was done to determine the safety and effectiveness of injecting the glutamic acid decarboxylase (GAD) producing gene directly into the brain to improve the motor function of people with PD who are not responding well to usual PD drug treatment. The method of delivering GAD involved using a harmless form of adeno-associated viral vector (AAV2) in order to deliver the gene directly to the brain.

Clinical Trial Phases completed: *Clinical Phase I* trial was completed with 12 people with Parkinson – or PWP with UPDRS score of 30 or more in "off" state and/or complications of L-DOPA pharmacotherapy (ClinicalTrials.gov registry number NCT00195143).

Clinical Phase II trial was completed with 45 PWPs. Twenty-two PWPs were randomly assigned to undergo surgery and receive an injection of the GAD gene while 23 PWPs were randomly assigned to the control group, undergoing the same surgery, but not receiving an injection containing the GAD gene.

Trial Information Source: The Primary Investigators and their research teams involved in these trials.

Reported in: Clinical Phase I trial : M.G. Kaplitt, A. Feigin, C. Tang, et al., Safety and tolerability of gene therapy with an adeno-associated virus (AAV) borne GAD gene for Parkinson's disease: an open label, phase I trial. (2007) *Lancet* 369, 2097–2105. Clinical Phase II trial: P.A. LeWitt, A.R. Rezai, M.A. Leehey MD, et al. (2011). AAV2-GAD gene therapy for advanced Parkinson's disease: a double-blind, sham-surgery controlled, randomised trial. *The Lancet Neurology*, 10(4) 309-319.

Findings: *Clinical Trials I and II:* All study participants survived the surgery, with reportedly minor side effects of headache and nausea for both Phase I and II trials. Findings in both trials indicated significant improvements in motor scores of the PWP who received the GAD gene.

Clinical Trial I: The outcome of this safety trial was positive with no dropouts or patients lost to follow-up and no adverse events related to the gene therapy were reported. PWPs displayed improvements in motor UPDRS and the effect was seen first at 3 months post surgery and persisted up to 12 months when the trial report was published.

Clinical Trial II: The efficacy and safety of bilateral infusion of AAV2-GAD in the subthalamic nucleus supports its further development for Parkinson's disease and shows the promise for gene therapy for neurological disorders.

Next Clinical Trial Phase: TBA

***Randomized, Double-Blind Study**—*a randomized trial is “Blind” (or masked) if participants are not told which arm of the trial they are in - experimental or control. The trial is considered “double-blind” when the study participants and the study staff are unaware of what arm each participant is in.*

DRUG TRIAL: Non-steroidal Anti-inflammatory drug (NSAID) Use and Parkinson Disease

Trial/ Study Purpose: An analysis was done with data from 22,007 male physicians participating in the Physician's Health Study. These participants provided detailed information on their current use of drugs for a period of 25 years, allowing researchers a unique opportunity to explore associations of both aspirin and NSAID use in relation to the eventual development of Parkinson disease in a portion of these participants.

Clinical Trial Phases completed: N/A

Trial Information Source: Driver, J.A., Logroscino, G., Gaziano, J.M., Kurth, T.

Reported in: BMJ 2011 online journal - BMJ 2011; 342:d198 doi:101136/bmj.d198

Driver, J.A., Logroscino, G., Gaziano, J.M., Kurth, T. (2011). Use of non-steroidal anti-inflammatory drugs and risk of Parkinson's disease: nested case-control study.

Findings: The physicians were followed for over 25 years as they documented the medications they used regularly, including aspirin and NSAIDS, as well as any diagnosis or development of illnesses or chronic diseases such as PD.

The authors attempted to address the inconsistencies in previous research studies – some that had findings supporting an association between a reduction in PD and the use of NSAIDS, while others indicated the exact opposite; that is, findings showed an increased risk of PD with the increased use of NSAIDS.

They determined that data from the Physician Health Study indicated a positive association between the use of NSAIDS and the development of PD. *However,* once they excluded NSAID use within 5 years of the PD diagnosis, *these associations were no longer evident.* They concluded that the use of NSAIDS within 5 years of being diagnosed with PD could have been caused by symptoms of the undiagnosed PD, and therefore were invalid (or confounding) data that could not be included in the overall analyses. The final conclusion of the researchers, based on this large set of long term data was: “Positive associations between non-aspirin NSAIDS or aspirin and risk of Parkinson's disease tended to disappear when analyses were limited to drug use greater than or equal to 5 years before the disease diagnosis.”

23 and Me and Michael J. Fox Foundation Launch New Study

The Michael J. Fox Foundation and the Parkinson's Institute have joined forces with 23 and Me, the leading provider of genetics services, in a new Parkinson's community that is focused on “paving the way to breakthrough discoveries about how our genes and environment influence Parkinson's disease.” They invite PWP to participate and the only requirements are to submit a saliva sample for genetic analysis and agree to participate in online surveys about your experience with PD. The power of the computer will enable them to assemble a diverse patient population of at least 10,000 individuals for research which was not possible in the past.

To learn more about this project, go to their web site www.23andme.com/pd or email them at the following address: pd-help@23andme.com.

INTERVIEW—DAVE CURTIN

By Jackie Dorwin and Jeff Lincoln

Dave Curtin is a CPWG Board Member and Information Technology Guru

Jackie: We'll start with a quick biography

Dave: I was born and raised in Yonkers, New York, and went off to college at Johns Hopkins University in Maryland, which was a change of scenery for me. Engineering had been my interest all my life so that's what I majored in while I was there. After graduation, I went to Sikorsky Aircraft for 5 years, first as a manufacturing engineer and later in information technologies. In the 60's, I switched to a timesharing company and I guess I stayed in variations of that line until I retired at the age of 61. It's been essentially computers and programming for my whole life.

Jeff: Tell us how you were diagnosed with PD?

Dave: In 2001, I had a tremor in one finger on my right hand when I would become fatigued and that was it. It was just a slight tremor, but I went to three different doctors and ended up at Institute for Neurodegenerative Disorders (IND) in New Haven, where I met Dr. Jennings. She asked questions, confirmed the utility of Sinemet in relieving PD symptoms, and ordered a SPECT scan, all of which indicated that I had PD.

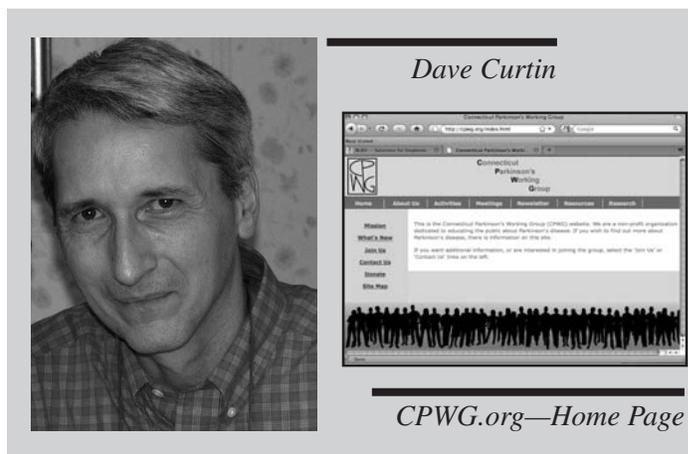
“My philosophy is that life is a crapshoot.”

Jeff: How did you feel when diagnosed?

Dave: I'm surprised at my acceptance of the disease. There are some people who get really upset when they find out they have been diagnosed with PD. My philosophy is that life is a crapshoot. What you end up with is usually beyond your control anyhow. There's no advantage to feeling sorry for yourself so you make the best of it.

Jeff: Every Person with Parkinson's Disease (PWP) has different symptoms.

Dave: The most bothersome symptom I have is fatigue. I don't feel like getting up and going through the long list of things to do each day. And the other symptom that worries me is the ability to express oneself and to find the right words. That's troublesome. Also, it's surprising how fast time goes by when you're retired. You have all this free time and nothing to do but somehow it gets used up! Often I just feel that I



don't get anything accomplished anymore. I don't know how much of the slowing down is due to age and how much is due to PD.

Jackie: Has the working group helped you fill some voids in your life?

Dave: CPWG? Yes, I think that is one of the things I feel is an accomplishment, that I've been helpful in keeping track of people on the mailing list.

Jeff: How did you find out about CPWG? You live somewhat far away.

Dave: Yes, that's a good question. I can't remember what reason I had to go to one of the meetings. I assume that I saw some advertisement in a doctor's office. I found that meeting and talking with other PWP was sort of liberating. At one point I used to worry about what people would think about my hand shaking in the supermarket check-out lane, as I try to write my name on those darn credit card machines. I have come to accept it and ultimately to ignore it. I don't care anymore what people think. It isn't productive to dwell on how lucky or unlucky you are.

Jeff: So let's talk a little bit about the computer program you run for CPWG. You developed it?

Dave: Well, I'm making use of an application called 'File-Maker' that gives you a lot of capabilities to generate an application, which is essentially a database of the people that attend the meetings, listing their names, addresses, telephone numbers, whether or not they want a newsletter sent, or a meeting reminder sent. So it's a pretty simple application. There is also the ability to keep track of people's donations so that they may be acknowledged.

Jeff: What kind of things can you do with this? Where can you go with it?

CALENDAR

CPWG ACTIVITIES:

CPWG Regular 3rd-Saturday-of-the-Month Meetings, 10:00 a.m.-Noon. Middlesex Hospital, Middletown, CT

May 21 — meeting will be on Tai Chi by Tom Cushing, instructor

June 18 — Diana Richardson, M.D., from the Veterans Affairs in W. Haven, will talk on PD.

July 16 — Program to be announced.

For additional information, call Jackie Dorwin (203-453-2655).

PARKINSON'S DISEASE FOUNDATION:

May 13 — Fri., 7:30 p.m., Fusco Distinguished Lecture: Michael J. Fox — "Always Looking Up: The Adventures of an Incurable Optimist". John Lyman Center for the Performing Arts, Southern Connecticut State University, 501 Crescent Street, New Haven, CT. Tickets: \$25/general public; \$125/person for the "Special Event Package". For additional information or to register call Betsey Galian 203-392-5598 or go online to galianb1@southernct.edu.

May 22 — Sun., 1:00 "2011 "Family & Friends" Walk-A-Thon / Festival and (New this year) Pooch Pageant At The Village at Mariner's Point, 111 South Shore Drive, East Haven. • A Walk-a-thon • Dance Demo and other "active" activities • Hotdog Roast, Make your own Sundae, Goodies, & Entertainment • Educational Program • Fun Activities (including face painting, balloon sculptures, bingo, raffle for a flat screen TV, AND, more). For additional information or to register call 877-282-7328 or go online to ddiaz@srhs.org

June 13 — Second Annual M.J.Petretta Foundation Golf Classic at the Clinton Country Club, Clinton, CT. Register by June 7th. Tournament is in memory of Ray Przygocki, an avid golfer and PWP. CPWG will share in the proceeds with several other health organizations. Support for this golf classic can be by registering and playing a round of golf, sponsoring an event or an award, joining a group for dinner, volunteering to help during the tournament, or making a contribution to the Foundation. For further information, contact Jackie Dorwin, 203-453-2655.

Dave: One thing that was suggested in the past, which posed an interesting technical question, was having a ride exchange by which some people were willing to *give* a ride to CPWG meetings, and other people could say they *need* a ride to a CPWG meeting.

The other thing that I've been involved with is the website that was pretty static for a few years. I tried to reorganize some of the pages. I've heard of some people in the group running into it and using the website. So it would be nice if there were more information on the website for people to use. It would also be valuable to have a list of skill sets associated with people and what they are able to do. You could then match the skills, such as legal or marketing skills, to a specific need. A project like this requires a lot of effort and it takes a person with a great deal of energy to volunteer and guide it along. Without someone in charge, nothing happens.

Jackie: What can you see down the road for you in the future?

Dave: The Parkinson's keeps progressing, very slowly in my case. I used to think that I could just pop a Sinemet and the symptoms would disappear, but I realize now that it is not the case.

Jackie: Any suggestions for people who are newly diagnosed?

Dave: I think it is helpful to speak to people who have had Parkinson's for awhile because there are misconceptions about what the disease is. Just the contact with others who have it would be helpful.

Jackie: It doesn't have to be at a support group meeting. It can just be for coffee or ice cream. Do you think being diagnosed with Parkinson's has changed the way your life is supposed to go?

Dave: I think it makes you more accepting of what life deals out to you. It sort of makes you humble. I think the worst disservice you can do to yourself is to get all upset about it and feel sorry for yourself. I've run into one or two people who have been very affected by the news and that is more of a problem than the actual disease. It's kinda funny. You wake up in the morning and you think, "Oh, I'm the guy with Parkinson's." You live most of your life without it, and then all of a sudden it's part of your life.

Jackie: Dave, sitting here with you, talking about some of our experiences with Parkinson's, has been one of the more pleasant side effects of the disease. Thank you for sharing your insights and your talents with us.



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PARKINSON'S AWARENESS MONTH

As April, the Parkinson's Awareness Month, draws to a close, the concept of designating this or any other month for special consideration bears some thought. Certainly we all appreciate the spot ads on T.V. that bring celebrity attention to the search for a cure. And, of course, we welcome the flurry of local educational programs designed to increase community understanding of the disease and raise the level of financial support for research. But when we think about it, we have to ask ourselves, "Why just one month?" *Every month*, and for that matter, *every day* is a PD awareness month or day for those who live with the disorder. As we turn the calendar page from April to May, we should not relax our efforts to bring this "awareness" to our families, our friends, our co-workers. For it is only when the disease comes out of the shadows and becomes a household word (as did Aids, Breast Cancer, and others) will there be the kind of grass

roots, year round pressure for an all-out "War on PD".

Ironically, although not using the term "War on PD", Ralph Lauren and Michael J. Fox have teamed up and have taken the metaphor one step further by designing a military type dog-tag with the MJF stylized fox logo engraved on it. It may be purchased for \$95 in many Ralph Lauren stores or online www.ralphlauren.com. 100% of net proceeds from the sale of these exclusive items will go to the MJF Foundation to support Parkinson research. Wearing one of these "unisex" chains is one way of bringing attention to the fight, but each of us must choose our own battleground.

And, yes, we should have a Parkinson's Awareness Month, but let us not forget that the enemy has no "awareness" of calendar pages!



DISCLAIMER: The content of this newsletter is offered to our readers solely on an informational basis and is not intended to support any medical treatment or advice. You are encouraged to review information regarding treatment with your physician. The opinions expressed are those of the writer or presenter and do not constitute an endorsement or approval by the CPWG Board or Newsletter staff.