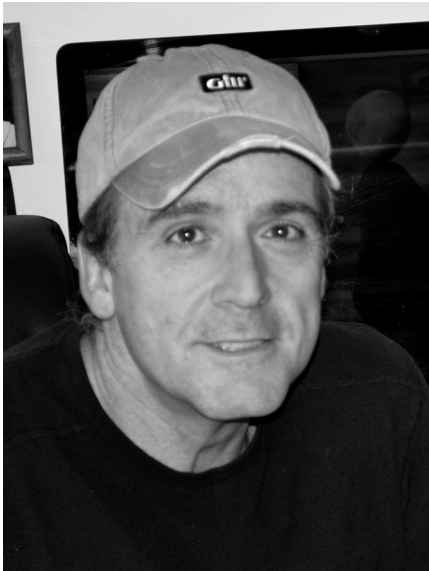


# AN OPEN LETTER TO CPWG



Andy Weatherwax—President, CPWG

## FALL 2012

### IN THIS ISSUE:

Open Letter to CPWG  
by Andy Weatherwax .....1

I've got what?  
by Jeffrey LaGrange .....3

M.J.Fox Foundation's  
Round Table Discussion  
by Judith Iovanna .....2

Calendar of CPWG and  
other PD Activities .....4

*Dear CPWG Members and Friends,*

*Well, we're finally off and running, or at least walking fast. I can hardly believe another summer has almost come and gone. Seems like just yesterday Jackie Dorwin and Tom Sullivan approached me with CPWG reins in hand, and asked if I would take them. I accepted and slowly but surely, with no fanfare, and little announcement, the change was made. I feel the need now for fanfare, fanfare in the way of gratitude.*

*To Jackie and Tom, on behalf of the membership of CPWG and all people with Parkinson's who have been touched by your courage, your great good will, dedication and hard-work, I extend my deepest gratitude. And to those before you especially Stan Wertheimer, thank you for all you have done for the CPWG and the Parkinson's community. You are pillars in our community and you have done something quite special, for this I am grateful. Thank you for your service to our cause. It is an honor to take the reins, along with VP Jeffrey LaGrange, we can only hope that our reign of service measures up. We are honored and humbled in our new roles.*

*That said, I would like to take the time now to introduce myself and share with you a bit of my story.*

*For those of you who do not know me my name is Andy Weatherwax. I was diagnosed with young-onset Parkinson's disease at the age of 38. I'm now,*

*gulp, 51. Wow, how time flies when you're having fun! Anyhow, I remember the day I was finally diagnosed. It was a Friday. Afterward, my wife, Josa, and I went for lunch at a small Mexican restaurant. We sat, silent. I looked across the table at her. She smiled and said, "We'll be fine. You can handle this, I know you can." I believed her.*

*That night I did not sleep much. It was a long, dark, and very lonely night. It was agonizing. My mind raced frantically, swinging like a monkey on a vine, from thought to thought through the thick Amazon jungle of my mind. A thousand questions and a thousand concerns swirled through my head as I pondered the meaning of this diagnosis.*

*I finally fell into a deep sleep shortly before sunrise. My eyes popped open at about 7:30 am. Although my sleep was short, it was deep; one of those sleeps that leave you wondering who and where you are when you wake. Slowly I pulled myself from the fog trying to recount the events of the day before. I remember tamales and beer at lunch and I remember Josa saying, "You can handle this." Handle this? Handle what? I remember the doctor's office. But why? What was it?*

*Then it hit me. Oh yeah, I have a chronic degenerative disorder of the central nervous system for which there is no cure! Yikes!*

*I had to laugh and laugh I did. Life comes at you sometimes and sometimes*

*Continued on page 2*

## OPEN LETTER Continued from page 1

---

*ya just gotta sit back and say Okay, I give! We had just gone through a very costly medical situation that rendered us nearly penniless (a story for another time). Additionally, we were dealing with my ill father who was in need of 24-hour care. I, as power of attorney, was having to manage his affairs and deal with family, doctors, attorneys, real estate agents, insurance agents, Title 19 and so on. On top of that I had just started a new business, we had just bought a new home and we were in the process of adopting a child. Now this. Okay, I give!*

*Like a mindfulness bell, the diagnosis woke me. I felt oddly prepared to get on with this next phase of my life. I saw a fork in the road and I saw it clearly. Two paths and just one answer. Either roll over and adopt a siege mentality, or embark on a new life journey. Everything in my life has prepared me for this moment. I don't judge my luck. I accept it for what it is, a simple fact and out of my control. My journey is set. Each step along the way is the only step. No looking back. No looking forward. There is only this step. And so it goes. I have Parkinson's disease. It is what it is.*

*And so it goes for us all. We, none of us, asked for this, but we got it. For as many people as there are with this illness there are just that many different flavors of the illness. No two of us are exactly the same. Likewise, there is a multitude of treatment regimes deployed by our neurologists, and a multitude of personal approaches to dealing with the illness. On top of all that we each have our individual circumstances. Regardless our situation, each of us is*

*waging our own personal struggle with suffering, whether you are a person with PD, a loved-one, a care-partner, anyone really. And while there is nothing so utterly intimate as our individual suffering, there is also nothing so utterly shared as this suffering. As long as we live and love, inescapable mental or physical discomfort will come our way. That's just the way it is.*

*Miles Davis once said something like, "Without silence there could not be music." Or maybe it was someone else, I'm not entirely sure. But I know he did say "Don't play what's there; play what's not there." My point is this, without suffering we cannot know true joy. If we can accept our suffering, not just put up with but embrace it, we can move on and live well today with our suffering. TODAY!*

*And so, as the new president of CPWG I will continue what others have started: To provide a comfortable and understanding forum in which you can share your stories and to provide a dynamic monthly program to help educate and support those affected by Parkinson's disease and their loved-ones so that we can all live well with Parkinson's disease TODAY!*

*I wish you all the best.*

*Sincerely,  
Andy Weatherwax  
President, CPWG*

## ROUND TABLE DISCUSSION

---

**By Judith Iovanna**

The New Haven Lawn Club was host to the Michael J. Fox Foundation's Luncheon and Round Table Discussion on May 30, 2012. About 150 people were present including members from CPWG and YYAPA's support groups.

After an enjoyable lunch, moderator, Debi Brooks, co-founder and executive Vice Chairperson for Michael J. Fox Foundation for Parkinson's Research, introduced the round table presenters. The focus of the round table discussion was: Improving Symptomatic Treatments;

Disease Modifying Therapies; Repositioning Drugs and Clinical Trials. Speakers were: Mark Frasier, PhD who spoke on accelerating PD research. Kuldip D. Dave, PhD, Parkinson's Disease expert and member on the MJFF staff and Danna Jennings, MD who spoke a study she is conducting regarding reducing dyskinesia. Also, Warren D. Hirst, PhD, Pfizer representative spoke on drug discoveries. They also emphasized the need to have PWP participate in clinical trials. 85% of clinical trials finish late due to recruitment challenges, many studies can only get one person with PD to participate in the trial. It is

*Continued on page 3*

# I'VE GOT WHAT?

---

*By Jeffrey LaGrange*

Let me begin in the beginning—although at this point I'm unsure when the beginning really was. Last I looked it was about nine years ago, could've been eight, but for the point of argument let's say nine. Nine short years ago. Or is it nine long years ago? Anyway after about four years of seeing a neurologist in Essex about twice a year who told me I had a resting tremor – which I did and it was very slight. I went to my primary care physician and told him I was tired of just getting the same “resting tremor” report and wanted some solid answers. Big mistake or the best thing I could have done? Both actually. So my doc set me up with a trip to Yale Neurology so a pro could look at this and I could find out what was going on. So big surprise.

---

*As I remember one of the Yale doctors said, “Parkinson’s won’t take your life, it will only change it.”*

---

After an hour of touching my nose with my index finger and tapping my foot real fast and being looked at by two doctors I got the word. “Sorry to say this Mr. LaGrange, but we're pretty sure you have Parkinson's.” Sorry to say this? I have what? I was both shocked and relieved. Do I cry or do I find comfort in knowing that Parkinson's is a very slow progressing disease and it won't kill me. As I remember one of the Yale doctors said, “Parkinson's won't take your life, it will only change it.” That was good to

know I think. I still wanted him to go away and be quiet.

So I left with a return engagement visit planned for six months in the future. No meds right now, we'll just wait and see.

I went back to Yale for about three years, always seeing a different movement specialist doctor since they rotated or moved around the clinic or something like that. I really hated driving to Yale and parking in that demonic parking garage where it seemed if you drove one inch to the right or left you'd plunge to your death four or five stories in the air. I hate parking garages as a general rule since they're usually one inch taller than I am, hot, smoky, noisy and they probably accelerate Parkinson's anyway.

So I had my doctor set me up to see someone at UConn where I am to this day. Happy with the guy and no dizzying parking lot around for miles. But I jump ahead.

So, back to my “sorry but you've got Parkinson's” day. I don't remember much more than the words spoken and leaving to come home and live my life in relative normalcy for as long as I could. Now what do I do? Who do I tell? Certainly no one at work – I'd be tossed out on the garbage pile within hours. Certainly not my son – he wouldn't understand. Keep it to myself I thought and just pretend this day never happened. Start reading up on everything you can find about Parkinson's. Knowledge is power isn't it, so get some power. O.K. So I did everything wrong. Or did I? Everyone is different and everyone handles news like this in his or her own way. What was best for me? Next issue I'll share that with you.

*Jeffrey LaGrange is a husband, father, active theater writer and reviewer, dancer, golfer, amateur singer and oh yes, PWP.*

## ROUND TABLE Continued from page 2

---

estimated that only 1 in 10 people with Parkinson's participate in clinical trials. The program was very informative. There was a question and answer session to conclude the program. Michael J. Fox and the staff at the Foundation are vigorously pursuing every avenue to find a cure for Parkinson's disease. The Foundation has funded over \$289 million in research. In 2011 MJFF received

more than 900 grant proposals and funded \$57 million in research. MJFF contributes \$.88 of every dollar they receive for research. Merck and Teva Pharmaceuticals also contributed to this event. For information on how to participate in a trial please visit: [www.michaeljfox.org](http://www.michaeljfox.org) and/ or [www.foxtrialfinder.org](http://www.foxtrialfinder.org).



195 White Birch Road  
East Hampton, CT 06424

**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.

## CALENDAR

---

### CPWG ACTIVITIES:

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

**September 15, 2012 — CPWG Open Mic Forum** This is the time to share your concerns, difficulties, victories—what ever is on your mind. It's an open exchange of solutions, support and understanding for PWP and their care-partners.

**October 20, 2012 — CPWG Presents Neurologist Alice Flaherty** One of the leaders in the field of PD treatment, Alice Flaherty, Dir., Movement Disorders Fellowship, Mass. General Hospital, will speak on treating PD with an eye to improved quality-of-life.

**November 17, 2012 — CPWG Panel Discussion: Spirituality and Illness** We look at illness and spirituality from many viewpoints. Speakers include Reverend Richard Allen, Senior Minister South Congregational Church, South Glastonbury, Middlesex Hospital Chaplain Dennis McCann and Buddhist Andy Weatherwax. Other speakers TBD.

### CPWG Keeps on Dancing for PD

**September 9, 2012 — Sun.,** Two classes—register for one today! 11:00 a.m.-12:15 p.m. & 2:00 p.m.-3:15 p.m. Lawrence A. Wien Experimental Theatre, Quick Center for the Arts, Fairfield University, 1073 North Benson Road. Free movement classes for persons with Parkinson's and their families, friends and care-partners will be held.

### Visit CPWG on facebook!

Join the conversation, keep up with events, and get the latest PD related news.  
Go to [www.facebook.com/CPWG.org](http://www.facebook.com/CPWG.org) and "like us" and spread the word!