CONNECTICUT PARKINSON'S WORKING GROUP News

FALL 2010

IN THIS ISSUE:

MOVIN' AND GROOVIN'

By Jackie Dorwin

We moved and we grooved and although we didn't find a cure for PD, we sure had a good time trying. Maybe we could consider it a novel therapy for those affected by Parkinson's disease. On September 19th, over 200 PWP (people with Parkinson's) and their friends and families came to our benefit event at Tango Restaurant in Glastonbury to support CPWG and its programs. When I walked in the door of the restaurant I was stunned to see so many people there, and more were on their way. The festivities started off at 4 p.m. with delicious hors d'oeuvres followed by a buffet that had something for everyone. The staff at Tango outdid themselves with the services they provided us.

CPWG Vice-President Tom Sullivan's opening remarks welcomed everyone and thanked those who put so much effort and time into this program. He also thanked Stan Wertheimer for his "vision that put an emphasis on active members who 'work' towards a better world" for the PD community. We do 'work' for PD, and that was evidenced by the success of this benefit.

The auction of over 50 donated items went smoothly under the gavel of Tom LeClair of Clearing House Auction Galleries in Wethersfield, CT. Tom, who happens to have PD, was an inspiration to many of us as he whipped through the list of very desirable goods and services in typical auction-speak, working the competitive bidding up to, and sometimes over, the actual value.

During dinner, Jack Chatfield, a drummer and also a PWP, with the accompaniment of two other musicians, showed us what we can do with our still-intact talents. All of this was leading up to the highlight of the day, a session of dance demonstrations by the folks from the Fred Astaire Dance Studio of Glastonbury. Our own CPWG Board Member, neurologist Dr. Toni DeMarcaida, the guiding force behind the whole benefit, educated us on the merits of dance as a proven therapy for PD. A dedicated student at the Fred Astaire Studio, she then wowed us all by dancing a lively tango.

Our day had many therapeutic ingredients in it, but the one that did the most for me was the feeling of comfort. I felt it when I walked in the door. We were all at ease with who we are. For four hours we came together, enjoyed each other's company, perhaps relaxed a bit, and we netted over $9,000 along the way. I'd say that was a good day of movin' and groovin'.

EDITORIAL

Letters to the Editor:

At last, Sunday, Sept. 19th, finally arrived and we were off to Glastonbury for a CPWG fundraiser. Little did we know that we would be transported to another world – Argentina!! We had a wonderful evening with Argentine food, music, and dance. After a delicious buffet dinner, a live auction was held and there was no lack of enthusiasm in bidding for the items. Finally, the main attraction of the evening began. Dr. deMarcaida, who was very much involved in the event, introduced us to the benefits of dancing and especially the Tango. She explained how the music and intricate steps helped with movement for PWP. Then Dr. deMarcaida and a partner [from the Fred Astaire Dance Studio in Glastonbury] surprised us all by dancing a Tango. Their interpretation of Argentina's national dance was beautiful and exciting. What an enjoyable evening we all had.

Carol Wright
Guilford, CT

Despite an earlier departure than we originally intended, "Movin' and Groovin' to Stop the Shakin'" dinner- dance at Tango was a wonderful experience. The staff was helpful, the food outstanding and the attendance exhibited the strength of the PD community.

Bob and Elaine Haddad
Columbia, CT

Editorial Staff:

Debbie Weinstein, *Editor*
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Jeff Lincoln, *Interviews and Distribution*
Steve Holahan, *Contributing Editor*
Dr. Toni deMarcaida, *Contributing Editor*
Judith Iovanna, *Calendar Editor*
Jackie Dorwin, *CPWG President, ex officio*

Editor's Note:

The Newsletter welcomes the addition of Jean LaGrange as art editor. She brings to the Newsletter a bright new look which we are proud to introduce in this issue. We also point out that this issue departs from our usual format of articles on current research to bring you personal accounts of various PD treatments. We invite your comments on all aspects of the Newsletter—send an email to debbie.weinstein@cpwg.org.

The Humorous Side of Parkinson's Disease

By Judith Iovanna

Dealing with PD since 1994, I had to develop a sense of humor. The event I wish to share is a reason for looking for humor in everything that happens with PD.

I was having dinner with cousins at our favorite Italian Restaurant in New Haven. The restaurant was crowded, as usual for a Saturday night. The waiter who was seating us seemed to be sprinting to our table. I held my breath as I zigzagged around tables (obstacles) and other servers who were precariously balancing huge trays piled high with delicacies. Finally, I let out a sigh of relief; I made it through the crowd and walked "normally" to our table. This was perfect. I was hoping for an uneventful evening. "I am just fine", the mantra I repeated in my head, trying to convince my brain that this was going to be great. But my PD brain wasn't about to make it easy for me. Sitting at the table, I chatted with everyone. I reached for my water glass, took a sip, and as I tried to put the glass back in its place, I knew my spatial sense was off!! Out of whack is more honest. The glass bounced off at least three other glasses, making a wonderful glass choir sound in my thwarted attempt to put the glass back on the table. Fortunately, my husband was able to right the glass before it crashed. I could feel all eyes on me. I silently repeated my mantra faster: "Just fine! Just fine, Just fine". Enjoying my surviving the glass incident, I breathed easier as the waiter placed a basket of hot spicy Italian rolls on the table. "Oh, my favorites" I thought as I reached for one of the delicious rolls. As if on cue, my arm, in true dyskinesia form, jerked up and the spicy Italian roll was airborne. It flew over my head, too mortified to see where it landed. I took another roll and pretended no one saw the spicy missile. Still not giving up, I repeated my mantra, "Fine, Fine, Fine, Fine" Why not put your hands on your lap, I thought, and wait for dinner. Great idea. I began to put my hands gracefully on my lap, but in doing so, my right hand struck the fork next to my plate and the fork catapulted into space. I quickly reached up, successfully catching the fork with one hand in mid air! With all cousins looking at me, eyes bugging out and mouths agape, I said with my best bravado: "Voila, MAGIC!" The table exploded into laughter. That is why you have to have a sense of humor with Parkinson's Disease.

TO KNOW...OR NOT TO KNOW...

By Debbie Weinstein

That is the big question today in the field of PD genetic testing. In recent years, researchers have identified several genes that are associated with PD but it is not clear yet exactly what role they play. However, since the current approach in the search for a cure seems to be focusing on early detection and finding people at risk for the disease before any symptoms are apparent, it becomes important to gather genetic profiles of a sufficiently large number of people, both with PD and without. The catch is this: since there is no cure for PD and no way to delay or prevent its onset, what would be the incentive to be tested and to find that one is at risk of developing the disease?

According to an article in the U.S. National Library of Medicine, most cases of PD "are classified as sporadic and occur in people with no apparent history of the disorder in their family. Although the cause of these cases remains unclear, sporadic cases probably result from a complex interaction of environmental and genetic factors."

On the other hand, current estimates of people with Parkinson disease who have a family history of this disorder range from 10 – 40 %. These familial cases are caused by mutations in the LRRK2, PARKIN, PINK1, SNCA and DJ1 gene, or by alterations in genes that have not yet been identified. Mutations in some of these genes may also play a role in cases that appear to be sporadic. The article goes on to explain that there are several ways in which these mutated genes may cause PD. In some cases, the mutations appear to "disturb the cell machinery that breaks down (degrades) unwanted proteins" resulting in an accumulation of un-degraded proteins that leads to the "impairment or death of dopamine producing neurons". Other mutations may cause problems in the neutralization of free radicals, the by-products of the energy produced in cells by mitochondria. This, too, can lead to the damage or death of dopamine producing neurons. There are also some cases where alterations in the GBA, SNCAIP, or UCHL1 gene seem to have modified the risk of developing PD.

Without delving into the complex patterns of gene inheritance, it is certainly clear that genetic testing is one way of identifying persons at risk for developing PD. In an effort to leap-frog the usual hypothesis-driven research, which is very slow and costly, Sergey Brin, a co-founder of Google, is counting on the ability of powerful computers to find patterns among the 10,000 PWP who have answered an extensive questionnaire and submitted their DNA to his wife's genetic testing company, "23 and Me". Motivated to speed the process by the discovery that his mother was diagnosed with PD and that he, too, carries the LRRK2 mutation, Brin has brought the cost of genetic testing down to a point where it would not be an inhibiting factor for those in his program. Although some in the traditional science community have questioned this approach, in a small test of the relationship between Gaucher's Disease and PD, Brin's computer analysis arrived at its conclusion in 20 minutes and was substantiated in an 8 month time frame whereas the conventional method took 6 years to determine and to prove the same answer!

On the other hand, current estimates of people with Parkinson disease who have a family history of this disorder range from 10—40 %.

This brings us back to our starting question: If we already have been diagnosed with PD, do we want to know that we are carrying a mutated gene which might increase our children's risk of developing PD? And if we do not have symptoms of PD yet, but have relatives with the disease, do we want to find out whether we are carrying the mutations which may increase our risk of ultimately developing it? And finally, even if we choose to be tested, whether as a participant in a study or just for curiosity sake, would we want to know the outcome and would we want to tell our children if we found any of the mutated genes related to PD?

Although doctors have used genetics to "foretell" disease risk for a long time, the precision of DNA makes some scientists refer to it as "toxic knowledge". The fear that a person learning of their increased risk of developing PD might do something drastic has been dispelled by various

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DBS: EIGHT YEARS LATER

By Steve Holahan

It has been almost 8 years since that frigid cold day in late January, 2003, when I had two holes drilled in my skull and Deep Brain Stimulation (DBS) electrodes implanted deep in a part of my brain called the subthalamic nucleus. A week later two pacemaker-like devices were implanted in my chest and connected to the electrodes by wires snaked under my skin. The 3+ volts of electric stimulus pulsing at 180 cycles per second (A light bulb on standard household current pulses at 60 cycles per second) is the magic bullet behind my DBS therapy. PD symptoms vary from person to person and even between left and right sides of the body. The stimulators are programmable as to voltage, cycle rate (frequency) and location. Each electrode actually consists of 4 separate electrodes, each in a slightly different location. They can be used singly or in multiple combinations to best suit a patient's mix of symptoms.

In the balance of this article, I shall focus on how my life and my PD have changed since undergoing DBS. However, it is nearly impossible to isolate just the DBS "cause and effect" from those of aging, cultural and economic security, and other health issues. I divide the time since my initial surgery into the following periods:

2003-2006—Superman

2006-2009—Superman gets a dose of Kryptonite (face the facts)

2009-Present—Balance (?)

With the benefit of hindsight, I can summarize the first post surgical period as "I am once again Superman without the Kryptonite around!" I fixed the roof, drove non-stop to Michigan, took down trees, bought a kayak, lifted weights at the gym, played hockey, etc. I could not believe what I suddenly was able to do. I was terrified that it was going to fail and I'd be back in my pre-DBS condition. I ate food with no thought of nutritional or health consequences.

This Superman phase was brought to an abrupt end by a dose of Kryptonite in the form of a mild heart attack, which I suffered in May, 2006. About the same time, my GP had ordered a bone density scan as part of my annual physical. The results indicated a growing problem with osteoporosis, which my mother and her mother had at the end of their lives. So while I had been able to cut back on or eliminate PD medicines because of DBS, new medicines were there to take their place.

With the onset of these other medical problems, I was no longer Superman. And although DBS provides tremendous therapeutic results for some of PD's worst symptoms, it is not a cure and does not stop the disease's progression.* The freezing, balance, and gait problems had returned and, coupled with my wife, Bernadette's rheumatoid arthritis, it was necessary to change our style of living from our high maintenance Glastonbury three-level colonial to an "all-in-one-level" house in Rocky Hill that provided all outside services.

We moved into our new place in September of 2008, just as Lehman Brothers was taking out Wall Street and Bernadette was diagnosed with breast cancer. Five days after Bern's surgery I was off to Beth Israel (Boston) to have my right stimulator replaced, as its battery was near exhaustion. Earlier, in January of 2008, my left side stimulator had been replaced for the same reason. Both replacements were scheduled well in advance during my periodic check-ups with the DBS specialist at Beth Israel. In both cases the surgery was quick with the only variable being Boston area traffic.

This post Superman or face-the-facts phase ended in May of 2009 with the sale of our Glastonbury house. I am not sure what to call this current phase of my life with DBS. Ideally, this should be the "balance" phase that I wrote about in a CPWG Newsletter article after my surgery:

> ***"The key word is balance and it is balance of movement, of muscle tension and flexibility, and of emotion that PD upsets. DBS has restored a great deal of physical balance to my life. The mental and emotional balance has been a struggle for me, in part because I just didn't [anticipate or] prepare for it. Having said that, I am***

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INTERVIEW—ANN WILLIAMS

By Jeff Lincoln

Stem Cell Treatment for Parkinson's Disease

Jeff: *I'm here today with Ann Williams whose husband Dave underwent Stem Cell Treatment (SCT) this summer in late July. Good morning, Ann. I assume that I will be asking the questions of you, as Dave isn't very vocal.*

Ann: No, and he's resting right now. Is this for the CPWG Newsletter?

Jeff: *Yes, in the same layout as the interview of me in the last issue.*

Ann: I read that, and it was really good. I'm a little concerned as I'm not really an expert on Stem Cells.

Jeff: *That's OK. Today we're going to do a fly over at 10,000 ft. If we need more detail, we'll go find an expert. Let me ask you a few questions about Dave as he was before he underwent the SCT procedure? When was Dave diagnosed with Parkinson's Disease?*

Ann: In 2006, about 4 years ago. You know, he might have had it longer. He said he hadn't been able to smell for the last 7 years.

Jeff: *What were his symptoms?*

Ann: They were very clear. He had lost his ability to write. He started having a masked face, with a lack of expressions. His walk was slow. And his energy level was very low. He was sleeping an awful lot. However, the first things were the tremor and his inability to write. He was about 68 when all of this happened. He's 74 now.

Jeff: *Did he go on the regular PD medicines?*

Ann: He tried everything, but none of them seemed to work. Now he's only on Sinemet.

Jeff: *On to the main topic. How did you learn about SCT?*

Ann: We were a little frustrated because Dave didn't seem to be getting better. So, I started looking on the Internet under "PARKINSON'S". Under this were Stem Cells. So I started reading up on Stem Cells and found an Institute in Germany, and many other places in Europe and all over the world that were doing Stem Cell Implants. At the time [2 years ago—Ed] there weren't any in the US. It took us almost 2 years to decide to go with Stem Cells. I went to a Web Site www.xcell-center.com. This site is very informative, especially the interviews with patients who have had SCT. In reading and forming my opinion, I came across a patient from the local area. I talked to him on the phone and he highly recommended the procedure. You can probably explore the Web Site above and find his BLOG.

Jeff: *Tell us how you actually proceeded to have the SCT procedure done.*

Ann: You just don't go. There is a format. First, you have to apply on-line. There is someone in the US that contacts you. The application is reviewed by doctors who typically ask for more information (MRI, Blood tests, etc.) I faxed all this stuff to them, and they replied that Dave was a candidate. Not everyone is a candidate. I talked to a lot of family and friends and we finally made the decision to go ahead. They gave me a date in the end of July.

Jeff: *Give us a brief narrative of your trip please.*

Ann: On the day before the procedure was to start, we flew to Germany and were picked up and taken to our hotel. All of the transportation costs within Germany were included in the cost of the procedure. Here is a very brief description of SCT:

- **DAY 1:** A simple blood test—10 minutes—anything seriously wrong with your blood?
- **DAY 2:** Withdraw a sample of Hip Bone marrow—one source of Stem Cells—10 minutes.
- **DAY 3:** Isolate Stem Cells from the surrounding marrow, concentrate, analyze them and select the strongest Stem Cells.
- **DAY 4:** Take a small sample of liquid from your spine, and Implant your own selected Stem Cells into your spine. You rest for about 3-4 hours.
- **DAY 5:** They follow up on you to see if everything is fine. That's it. We stayed an extra week.

Jeff: *How much did this procedure cost.*

Ann: $9,000. When (or if) this procedure is accepted for the US, the expected cost is $35,000 to $50.000! None of these costs are likely to be covered by Medicare.

Jeff: *Tell us about the aftermath of the operation.*

Ann: After the operation, Dave was supposed to drink about 3 liters of liquid a day. He was having a difficult time

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TO KNOW OR NOT TO KNOW... *Continued from page 3*

studies. Furthermore, for some people, knowledge is empowering, enabling them to take advantage of any developments in research and/or to explore life-style adjustments that might prepare them for future changes.

There are, however, other concerns that might make a person hesitate to be tested. For those not in a study, the cost can still be significant. Then there is the possibility of lab error resulting in false positive (or false negative) readings. Furthermore, given an accurate positive result, the jury is still out as to the percentage of risk that it represents. Another important consideration is the question of privacy—who will get to know this information and what effect will it have on job security, insurability, and other aspects of one's life (and the lives of one's offspring).

The answer to this conundrum lies within each of us. Do we contribute our DNA to science in the hope that it will speed the race for the cure? Do we have the test but keep the results to ourselves? Do we have the test and share the results, good or bad, with our children so that they can decide whether to explore their own risks? Or do we wait for a solution to come along that will correct or at least disable the harmful effects of possible mutant genes?

We invite you to express your thoughts on this subject by sending an email to our Letters to the Editor Column at debbie.weinstein@cpwg.org.

To learn more about PD and genes, go to:
http://ghr.nlm.nih.gov/condition/parkinson-disease.

Or to find out more about Sergey Brin and "23 and Me", go to:
http://www.23andme.com/about/press/20090312/.

Definitions

We all hear references to stem cells and genes in the reports of current medical research. In an effort to clarify any confusion of the two, we offer the following explanation of the terms.

STEM CELL: A "generic" cell that can make exact copies of itself indefinitely. It also has the ability to produce specialized cells for various tissue in the body, such as heart muscle, brain tissue, and liver tissue.

Two main types: 1. Embryonic Stem Cell—obtained from either aborted fetuses or fertilized eggs left over from InVitro fertilization. These are useful because they can produce almost every tissue in the body. 2. Adult Stem Cell—not as versatile because it is specific to certain types, such as blood, intestine, skin, and muscle. Found in children and adults.

Uses: 1. Possibly generate new tissue when lost. Possible cure for many diseases.

2. Gain better understanding of how genetics work in early stages of cell development.

3. Useful in testing and development of drugs. Special tissue such as heart could be created and then used to test drugs.

STEM CELL TRANSPLANT: Also known as bone marrow transplants, use adult stem cells. These transplants have been performed since the late 1960's. Use of embryonic stem cell transplants has not been perfected for humans yet.

GENE: A hereditary unit consisting of a sequence of DNA that occupies a specific location on a chromosome and determines a particular characteristic in an organism. Genes undergo mutation when their DNA sequence changes.

GENE THERAPY: The treatment of certain disorders, especially those caused by genetic anomalies or deficiencies, by introducing engineered genes into a patient's cells.

DBS *Continued from page 4*

not sure how I would have prepared. Like many of life's journeys this may just have required me to put on the boots and make that hike. It is not over yet but I do sense more balance and control in my life. A life made much more livable because of DBS therapy and which, I hope, will prove how wrong the French playwright, Moliere, was when he said, 'Nearly all men die of their remedies, and not of their illnesses.' "

Maintaining a sense of balance in our lives is critical, especially in these unbalanced times.

*****For a complete discussion of DBS's effect on symptoms, see page 17 of the Parkinson's Disease Foundation's booklet *Deep Brain Stimulation for Parkinson's Disease.*

Web Sites

www.cpwg.org

This is your website—visit it for updates on our activities and other useful information. Lost your copy of the last Newsletter before you finished reading it? No problem—back issues are available on our website.

www.PDTrials.org

Lists clinical trials for PD with contact information and criteria for participation.

www.indd.org

This is the web site of the Institute for Neurodegenerative Disorders in New Haven, CT., a "non-profit organization dedicated to improved treatments, diagnostic tools and educational programs for neurologic disorders such as Parkinson Disease…through clinical research."

INTERVIEW *Continued from page 5*

swallowing. So he didn't listen to the doctor. And he started not eating too much. This was when we were still in Germany. He had a lot of neck pain on the plane so he didn't sleep on the way back. Dave was very tired and he had a little setback [dementia – Ed]. We decided it was due to exhaustion from the trip. The doctors said that people with PD, Alzheimer's, ALS, etc. don't react well to changes in environment.

I would advise them to talk to as many individuals who have experienced the procedure as possible.

Jeff: *What about results?*

Ann: The doctor in Germany said that it takes 2-3-4 months for the Stem Cells to show themselves if they are going to show themselves at all. It's not successful for everyone [statistically ~75%—Ed] . The Stem Cells have to migrate up through tough neural material. That's where we are now waiting for the Stem Cells to show. There hasn't been any definite evidence. However, his toes have uncurled.

Jeff: *How is Dave doing? On balance is he better, worse or about the same as before SCT?*

Ann: He's not worse, but I'm not sure where we are for PD. At Yale, he has been diagnosed with Lewy Body Dementia. Physically, he's doing well. Mainly, we try to exercise, do yoga, etc. This helps with his mobility, but the cognitive is a big question mark.

Jeff: *One last question. What advice would you give to someone considering SCT?*

Ann: I would advise them to talk to as many individuals who have experienced the procedure as possible. The more you learn, the more confident you will be in your own decision one way or the other. Doctors in the US know very little about it, as it hasn't been done here. So the best advice I have is find people who have gone through the procedure.

Jeff: *And pick their brains, so to speak [I couldn't resist"—Ed]. I think that what I will do is to visit with you again in about 3 months, Hopefully, we'll have happy news to report back. Thank you for spending time with me.*

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Write your Representatives in Congress!

Senator Christopher Dodd
Russell Senate Office Building
Washington, D.C. 20510

Senator Joseph Lieberman
Hart Senate Office Building
Washington, D.C. 20510

DISCLAIMER:
Articles in this newsletter are for information only. Any question of treatment should be discussed with your physician.

CALENDAR

CPWG Activities

November 20th—
CPWG Regular Meeting, 10:00 a.m.
Middlesex Hospital, Middletown, CT

Police Officer Michael Fitzpatrick from the Portland Police will be our guest on Saturday, November 20. Officer Fitzpatrick will address concerns that many of us have and answer questions on police procedure if anyone with Parkinson's gets stopped while driving or needs police help.

December —
No Meeting in December.

January 15th—
CPWG Regular Meeting, 10:00 a.m.
Middlesex Hospital, Middletown, CT
Open Mike Meeting

Parkinson Dance Classes Schedule

Middletown	Middletown CT Senior Center Monday 1:30—2:45 p.m. Instructor: Laura Richling Phone: 203.675.2930
New London	Connecticut College Wednesday 10:30—11:45 a.m. Instructor: Rachel Balaban Phone: 401.261.7062

Parkinson's Radio Station

Has been broadcasting via the internet since 2008. Their studio is located just outside Chicago overlooking Lake Michigan. They run two programs: PD Talk Live and Parkinson's and Me. The following link will take you to their home page www.parkinsonsradio.com which will give the background of their programs and links to listen to them. (CPWG includes this link as a service to its members but is not responsible for the content of the programs and does not endorse any of its positions.)