

Golf Classic and CPWG

By Jackie Dorwin

SUMMER 2011

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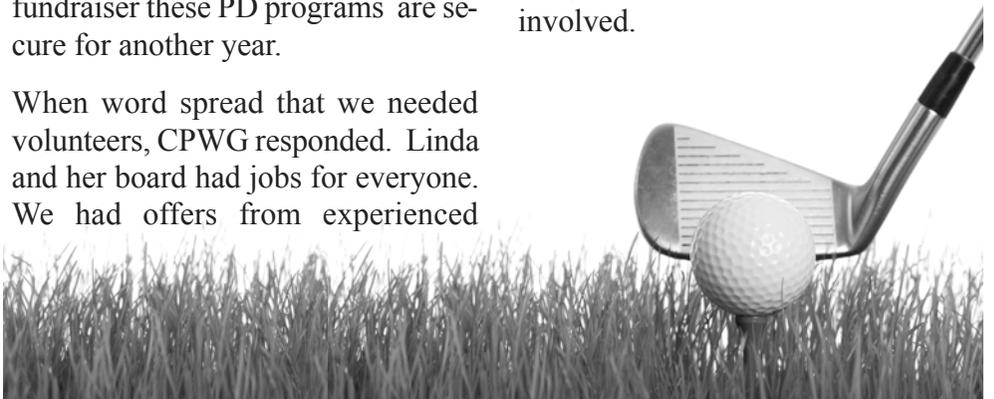
Linda Remington said it would be a beautiful day to golf and she was right! What a day it was! The MJ Petretto Foundation's 2nd Annual Golf Classic was held at the Clinton Country Club on June 13. The Foundation's mission is to help fund local organizations that support education, health and quality of life to build stronger Connecticut communities. Proceeds from this year's Golf Classic benefitted Gaylord Specialty Health Spinal Cord Injury Program and the VNA Community Healthcare Parkinson's Exercise class and Parkinson's Caregivers programs.

Linda's dad, Ray, passed away unexpectedly in December. He had PD and he participated in just about every PD-related activity around, including CPWG, the VNA exercise class, and golfing in Portland with other PD golfers. In honor of Ray, the MJP Foundation board decided to support these vital Parkinson's programs which were in jeopardy due to recent Medicare cuts. As a result of this fundraiser these PD programs are secure for another year.

When word spread that we needed volunteers, CPWG responded. Linda and her board had jobs for everyone. We had offers from experienced

golfers who could help out anywhere. ('Even though you are starting at the sixth hole you will still get to play all eighteen holes.') We heard from people who had never played the game, wanted to help, but needed a bit more guidance. ('No, the golf cart cannot be driven on the green.') A few days before, some of us stuffed the gift bags with donated goodies. (Pencils with erasers for keeping score....) Others came after the golfing was over for a wonderful Happy Hour, dinner and auction. The live band kept our toes tapping, and many generous items were auctioned off. (A ten-day African Safari in Kenya?!) One of our members drove all the way to Clinton from Southbury for the day, and there were big smiles on the faces of those who rode a golf cart around the property and saw the gorgeous landscaping.

Together we enjoyed a very successful day. Yes, it was a beautiful day for the Foundation, the VNA, CPWG, and the entire Connecticut PD community. We were pleased to be part of it, and our thanks to all who were involved.



EDITORIAL

NEWS FROM THE FILLING-IN EDITOR— JACKIE DORWIN:

Family First

Deb Weinstein spoke with me several weeks ago about this issue of the CPWG newsletter and asked if I could take care of it for her as she had family matters to tend to.

Since we have always said “Family First” I agreed to help out. Fortunately, we have a very kind readership who will understand why this edition is not our usual length and lacks Deb’s remarkable touch.

This might be a good time to ask your opinion of the newsletter’s parts that are not printed this issue. Do you miss them? This includes the interviews, book reviews, and research reports. Can you give us a few suggestions?

Hopefully this issue will give you information that you can use, and you all have my best wishes for comfortable days ahead.

Condolences

Pat Gerace came to our first CPWG meeting in 2000 and she kept on coming, at least in spirit, until she passed away in July. She was an elementary school teacher by training and the patience she needed for that job carried over into her participation in CPWG and in her family life. Not too many people knew that her husband was diagnosed with Alzheimer’s disease and she retired from teaching to care for him after she had been diagnosed with PD.

In the earlier years of CPWG Pat saw a need to organize our mailing list so she taught herself how to use a computer. A short while later CPWG had printed labels for our mailings and she handled the maintenance of the list, ensuring that everyone’s address was up-to-date. Pat was also quite Irish. A music therapist came to one of the support group meetings, and Pat agreed to join her in researching the effect of music on the Parkinson body. The research determined that Pat’s body relaxed most effectively to Irish music and we spent quite a bit of time listening to ‘When Irish Eyes are Smiling’ and Danny Boy.’

Pat’s strength was teaching and she introduced me to the phrase ‘educable moments.’ She found these moments everywhere and used them to tell people about PD and CPWG. In her own quiet way she was involved, innovative, and an inspiration. Our condolences to her family.

Donna Diaz

What will the Connecticut Parkinson community be like without Donna Diaz telling us ‘We meet, we eat.’ Donna has recently sent out a letter telling us that she is no longer working as the Information and Referral Coordinator for the Connecticut Chapter of the APDA. She has taken a position at Quinnipiac University in Hamden in their School of Nursing. We will miss her but know that she is well-suited for this new adventure. Our best wishes to her!

Something to think about

*The U.S. Administration on Aging has designated 2011 as the Year of the Caregiver. “National research has shown that caregivers are everywhere and their numbers are growing. For example, 66 percent of older people with chronic disabilities are cared for by a family member, and 65 million people provide care for a chronically ill, disabled or aged family member or friend each year.”**

One year is not nearly enough time to acknowledge the carepartners in our lives, but we would like to let them shine for a while. Another national group will be celebrating November as a carepartner month, and CPWG will do the same. Please brainstorm (we can still do that!) for group activities, tangible items, or bright ideas. Some thoughts are a cruise up and down the Connecticut River; a caregiving book and bookmark for each carepartner; start a ‘No Neckties’ fund; donate a book or video for the CPWG library in honor of or in memory of a carepartner. Let us know your ideas.

**excerpted from Parkinson’s Post, July/August 2011*

LETTERS TO THE EDITOR:

I have a medical PWP/medical problem that I haven’t been able to find a remedy for. As a group of people I’ve known for a while who also have a great deal of PD experience, I thought I’d ask if anyone might have an idea of what’s going on.

The basic problem is tiredness/fatigue (feeling lousy). What makes my flavor different is that it is worse in the morning and gradually gets better as the day progresses until I feel almost myself at bedtime. This is consistent each day

I’ve seen my PCP and neurologist, had a sleep study, searched the Internet etc. but haven’t found a malady with same characteristics.

*Thanks for any ideas.
Anonymous Member*

RESEARCH PROGRAM

By Judith Iovanna

Recently I had the opportunity to participate in a Parkinson's Disease (PD) Research Study. I volunteered to be a part of a study investigating the relationship of PD, blood pressure, and cognition.

In PD, the blood pressure can plummet at times due to medicine and/or postural positions. Some People with Parkinson's (PWP) experience this drop in blood pressure when rising from a seated position to a standing position and sometimes after taking their medication.

The study was conducted at Beth Israel Deaconess Medical Center in Boston, under the direction of Dr. Christopher Gibbons.

Participants chose the study that interested them and off they went.

Steve DeWitte, president of Young Onset Parkinson's Disease Support Group organized the trip. He arranged for a van with a professional driver to pick up participants at designated locations along I 84 and to drop them off at the doorstep of the hospital and return them to their departure stop on the way home.

Upon arriving at the hospital, we were greeted by a very friendly staff of doctors and research students (PhD programs) who were eager to make our stay as pleasant and comfortable as possible.

After the initial introductions we were treated to a very nice lunch. When lunch ended, we were escorted by staff to one of the four studies that were being conducted that day. Along with the blood pressure trial, a vision, skin biopsy, and a 'goose bump' trial were on the agenda. Participants chose the study that interested them and off they went.

I was placed in the room where the study on PD/blood pressure was going to take place. Justin Centi was co-

ordinator of this trial. He was trying to determine if there is a correlation between low blood pressure and cognitive function in PD.

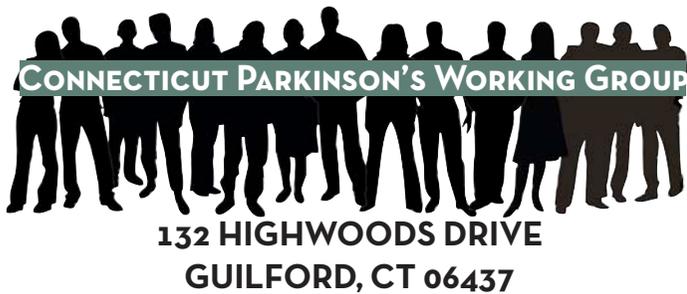
After answering a few questions, several leads were attached to my body. These leads were then connected to monitors that would be measuring heart rate and blood pressure. I was asked a series of questions while lying down. Then after being secured to the exam table, it was put in motion and I was upright. Justin asked another series of similar questions when I was standing to determine if there is any evidence that there is a difference in how the participant answers similar questions in a lying down and/or standing position so a comparison can be made on their supposition. While the questioning was going on, the wires streaming from my body and connected to the monitors were buzzing and beeping, rapidly collecting data. The entire study took about 2 ½ hours. (The time flies!) Then, as quickly as it started, the melodic symphony of sounds abruptly ended and Justin announced the study was complete. I was pleased to have been a part of the research.

Volunteers are needed for research! If you are interested in volunteering in a research program, let CPWG know. It is a rewarding experience.

CLINICAL TRIALS

The following information is reprinted with permission from the Institute for Neurodegenerative Disorders newsletter 'Spectrum, Summer 2011,'

Healthy volunteers are critical to the outcome of clinical trials. Healthy volunteers provide critical data in clinical research studies. A healthy volunteer is one who has no significant health problems. Although volunteers derive no direct benefit from participating, the data they provide can be compared to those who have a specific condition. These volunteers are often referred to as the control group. Healthy volunteers are often compensated for their time. To become part of our registry of healthy volunteers please e-mail bfussell@indd.org.



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:

September 17 — Sat., **Parkinson's Advocacy in Connecticut** sponsored by Young Parkinson's Support Group & CPWG Location: UCONN Health Center, Stem Cell Institute Farmington, CT. There is much we can do to support Parkinson's programs and research if we know where to go and who to talk to. This collaborative program will give you pertinent information. More regarding this meeting will be mailed out shortly. Guests will include representatives of Parkinson's Action Network, Young Parkinson's Support Group and the Connecticut Legislature. Any questions or concerns please contact Steve DeWitte 860-868-7966 or Jackie Dorwin 203-453-2655.

October 15 — CPWG Regular 3rd-Saturday-of-the-Month Meeting, 10:00 a.m.-Noon. Middlesex Hospital, Middletown, CT. Program to be announced.

Come Cruise with Us—We are planning a cruise on the Connecticut River sometime this fall. If you are interested in coming or helping to plan please contact Judy Iovanna at 203-237-4368.

VETERANS ADMINISTRATION:

September 13 —Tues., 12:00 p.m.-1:00. **Lee Silverman Voice Technique** presented by Diana Richardson, MD. in West Haven, CT.

September 27 —Tues., 12:00 p.m.-1:00. **Wii Fitness Club Body Re-Building Basics** presented by Diana Richardson, MD. in West Haven, CT.

For additional information contact the VA website <http://www.connecticut.va.gov/click/events/classes> or call Diana Richardson, MD or Jackie Wolf, RN 203-932-5711, ext 5189

OTHER:

October 20-22 — Thus.-Sat., **Clinical Research Learning Institute** Parkinson's Disease Foundation Florham Park, NJ. Participants learn from leading clinical research experts about the science of PD and the clinical research process. For more information contact www.pdf.org/crli or 800-457-6676.

MISSION STATEMENT The mission of the Connecticut Parkinson's Working Group is to provide education and support to those affected with Parkinson's disease and to collaborate with the medical community to enhance treatment and research of Parkinson's disease