

CENTRAL NEW YORK PARKINSON'S SUPPORT GROUP, Inc.

Vol. 20 No. 1 January 2011

Meeting Schedule – 3rd Tuesday – 12:30 PM

Presbyterian Home of CNY

4290 Middle Settlement Rd., New Hartford, NY

Mailing Address

P.O. Box 181 New Hartford, NY 13413

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Calendar of Events

January 18, 2011

Guest Speaker – Tom Lorenz

Chaplin – Presbyterian Home of CNY

Topic – Spiritual Journey of Challenge & Loss

February 15, 2011
To be announced

March 15, 2011
World Parkinson Congress Sharing Program
Presenters – Pat Duciaume & Joe Leary







The content of this newsletter is strictly for informational purposes and is not intended as medical advice for the treatment of Parkinson's disease. For individual problems, consult your own physician.

No Parkin' Zone Staff

Editor: Nancy McCaffrey

<u>Production Staff</u>: Stuart & Lois Greene. Barbara Grogan, Ann Lenio, John & Thea Matterese, Pat Moylan, Myrtleann Seifried, Hank & Rose Marie Taylor

A Message from the President

I am past the halfway point as President and it is indeed time for reflection. I am thankful that our organization is maintaining its promise to be here for one another. We recognize and attempt to meet the diverse needs of our members in so many different ways. And, I am equally thankful that our organization is growing. I understand that with this growth, we are challenged to make decisions about what to do and how to accomplish our mission.

Let me leave you with a question and possibility.

Are we doing enough to educate the public about Parkinson's disease? I am imagining an enhanced effort to reach out to the public in a variety of settings. Initially, would it be possible to choose one month in the fall with outreach to every supermarket in the area? Using a health fair format, teams of people could serve ambassadors and provide formal and informal information about Parkinson's disease. In subsequent years, this focused effort could extend to cafes, convenience stores, educational institutions, fast food establishments, fitness centers, malls, medial centers. places of worship. rehabilitation centers, restaurants, senior centers, shopping centers, skilled nursing facilities, and any and all other places where we can meet, greet and educate the public. Let me know what you think.

Many hands make light work. Let's make this a memorable year!

Pat Duciaume

Let's make 2011 a banner year!!

Make a Note

2011 is here and CNYPSG has a new address, phone number and e-mail address. Please make a note of them for future reference.

New Address – P.O. Box 181 New Hartford, NY 13413

Phone - 272-2267

E-mail address – Pduciaume@aol.com

Why Attend a Support Group?

If you have never been to a support group meeting, maybe it's time for you to consider attending a local PD group meting, no matter what your age. Support group members understand your struggles because they face or have faced the same challenges.

If you are reluctant to attend a PD support group because you will see others with advanced cases, and you don't think you can handle that, talk on the phone with others who have PD. Or, start a small group that gets together for lunch or coffee. Being with others who have PD may alleviate fears rather than worsen them. It is encouraging to see people with PD still driving, working and caring for their families.

Being in a group setting will also give you the opportunity to get lots of helpful tips and ideas on how to cope with many situations. Most groups provide informational programs or entertainment. It is most important that you learn all you can about Parkinson's disease whether you have PD or are a caregiver!

You might even find the meetings can be FUN!!

WOW!! What a Party!!

The annual CNYPSG Holiday
Party held on December 21st turned out
to be a fantastic SURPRISE bash
honoring two very surprised couples!!

President Pat Duciaume welcomed the attendees. The first surprise was the appearance of Marge Moylan's brother, David Fulmer, followed by Ed and Nancy McCaffrey's son, John. That was the first clue the party was special.

Tony Joseph reflected on his association with the Moylans and McCaffreys. Sharon Kelley read her poem "Holiday Appreciation." Baden Mudge's many kind words brought back many fond memories of past events.

The Support Group and the Presbyterian Home staff provided much wonderful food and best of all; we were surrounded by many loving and caring friends! Musical entertainment was provided by Yesterday's Senior Ensemble.

Then the party was topped off with each couple receiving a lovely plaque and beautiful crystal lamp which will always serve as a reminder of our CNYPSG friends.



HAPPY NEW YEAR!!

Thank you!!

To CNYPSG,

Thank you so much for everything you did for us at the holiday party in December. What a surprise! We were deeply touched. We are very appreciative of the support we have received over the years and it's because of our membership that we have been successful as a group.

Thanks again for being you. We mean that sincerely and your recognition of our efforts will always be remembered. We will always be committed to spreading the message about Parkinson's disease. Keep up the good work!

Pat and Marge Moylan

Dear CNYPSG friends.

Words cannot express our gratitude for the beautiful party you surprised us with! The biggest surprise was probably having John walk in!

Everything was wonderful – the food, the entertainment and of course, the fellowship!!

We truly appreciate the many kind remarks and all of the membership support throughout the years.

The beautiful lamp will always be a reminder of our many CNYPSG friends!

Please know we will always remember this special day!

Gratefully,

Ed & Nancy McCaffrey

Board of Directors

Meeting Schedule: January 7, 2011 February 4, 2011 March 4, 2011



A hobby as defined by Webster's Dictionary is "an activity engaged in for pleasure and relaxation during spare time." This can be something as simple as collecting buttons and matchbook covers (remember them) to something more technical such as studio photography or radio controlled airplanes. I like building scale models of cars and airplanes. I was doing this before my diagnosis of PD and I continue to stay with it despite the PD. Yes, it takes me a little longer to complete a project now working around bouts of tremor, rigidity, and dyskinesias. It may well take a whole afternoon to get a car's interior together or a wing assembly together, but when completed; my accomplishment is pronounced much more because overcame my physical challenge.

At first it was frustrating, but I have learned to adapt with this hobby as my PD symptoms present themselves. I have added various tools and build jigs to my modeler's kit to work around these problems like spring type clothes pins and alligator clips and a small piece of pegboard to hold parts. The most expensive item I added was a fluorescent drafting lamp with a magnifying glass and I found that at a garage sale. Sometimes no matter what you do or how hard you try, your build session just does not go well at all. Maybe it's a bad symptoms day or maybe the difficulty of the item you're working on. Whatever the reason, don't let the frustrations get the better of you. Just walk away from the problem for a while, an hour, two hours, or the whole day if you want. It's your hobby and it's supposed to be relaxing, not raising your stress levels. I have left projects for months only to come back and find the problem was easily cleared. Conversely, I have also had to raise the white flag on a project and get help with it or specific parts of it. I have found this to be beneficial also in that it can be a great way to spend quality time with friends and family.

Start out with something simple. There are a lot of snap together kits out there that do not require glue. They can be quite detailed and look great when they're finished. Glue kits can run from the simple to the very complex in terms of assembly. Choose your project according to your abilities and frustration levels, (frustration levels being the key words here). Remember, it's a hobby!

Parkinson's will affect everything you do in life. Keep up with your hobbies and work around or through your symptoms. Adapt where you need to but do not give up without a fight. Completing a project and showing it off to others is great therapy. Go ahead and try it. If you need help, I will lend a hand

By Joseph A. Leary Dx /PD 04 / 04

A letter from a special friend of CNYPSG

Dear Mr. Moylan:

Happy Holidays from HMS Host! As you know each year when I am able, I collect donations from our customers for the CNY Parkinson's Support Group. As a long time Parkinson's caregiver, I know how important it is for the families and those with PD to have support.

Please accept this donation for \$1778.00 from the customers of the Indian Castle Plaza. I will continue to ask for donations on behalf of the CNYPSG. If I can be of assistance in any manner, please contact me at the numbers listed below.

Have a Very Blessed Christmas and Healthy New Year!

Sincerely, Anthony Salvaggio Store Manager Indian Castle Travel Plaza

Editor's note:

Our sincere thanks to Mr. Salvaggio for his wonderful efforts on behalf of CNYPSG! We are truly blessed to have you as a friend!! **Thank you!**

TOXIC CAUSES OF PARKINSON'S DISEASE

Viartis - There are now fourteen known toxic causes of Parkinson's Disease: pesticides (Paraquat, Rotenone, Maneb), solvents (Trichloroethylene, Toluene, N-Hexane, Carbon disulfide), MPTP, Mercury, Manganese, Copper, Carbon monoxide, Lead, Cyanide.

Although Agent Orange is widely claimed to be a toxic cause of Parkinson's Disease, not even one study in the entire medical literature has ever shown that to be true.

Toxicity has the potential to be the sole cause of Parkinson's Disease. To very varying extents, toxicity can also be a partial cause of Parkinson's Disease. Symptoms normally develop when toxic exposure occurs or soon after, or gradually increase over time as exposure to toxicity persists.

Symptoms do not develop years or decades after exposure as is often claimed. In fact, there is a tendency for toxic effects to decline over time, but with some toxic substances that can take years.

The prevalence of Parkinson's Disease that is due to toxicity is not known. However, the evidence suggests that the number of people whose Parkinson's Disease is due to toxicity is very low, being the exception rather than the norm.

The toxic causes of Parkinson's Disease each cause different symptoms because of the different biochemical means by which toxicity is caused, and because of the other biochemical functions that each of the particular toxins affects.

In order to cause Parkinson's Disease, the level of toxic exposure usually has to be either acute or chronic. Mild exposure to some of the known toxic causes would have no noticeable effect.

Some other potentially toxic causes of Parkinson's Disease, such as copper and manganese are actually beneficial to health in normal quantities, and can only cause Parkinson's Disease in very large quantities. For a completely comprehensive, fully referenced, up to date and printable

summary of each of the toxic causes of Parkinson's Disease, go to Toxic causes of Parkinson's Disease

Source: Northwest Parkinson's Foundation Website

People suffering from what's called "dysphagia"

University of Florida - People suffering from what's called "dysphagia" have difficulty swallowing and may experience pain while eating or drinking.

Patients with Parkinson's disease often have dysphagia and that can lead to substances getting caught in their airways, causing infections and potentially death.

Now a new University of Florida study shows Parkinson's patients can improve their swallowing with training. Researchers say exhaling in this simple device can strengthen the muscles in your throat, which leads to improved swallowing.

Dr. Michelle Troche/UF speech language pathologist: "We found that people who had a degenerative swallowing problem were able to improve their swallowing with this device. Not just give them a crutch, not just a compensation, but actually fix a portion of the problem and make them safer swallowers."

Experts consider the ability to swallow essential for survival. UF researchers say it is important to find new ways to deal with swallowing problems early to improve quality of life for people coping with Parkinson's.

Dr. Michelle Troche/UF speech language pathologist: "I think for a long time we thought if someone had a degenerative disease and something goes wrong, you can't fix it. That is not the case; we don't believe that anymore. Our brains can change even in spite of some degenerative neurological disease."

Researchers say doctors could also use this therapy for people who suffer strokes or other neurodegenerative diseases like multiple sclerosis.

Source: Northwest Parkinson's Foundation Website

The Group Scoop

MEETING NOTES



A Senior Reader Theater group was our guest at our October meeting. They gave an interesting presentation of very entertaining material. Our own Sharon Kelley was one of the presenters and we thank her for introducing us to the group! Following their presentation, the people with Parkinson's and the caregivers met with their individual discussion groups.

At the November 16th meeting, the group viewed a video presentation produced by the Parkinson Disease Foundation, "You Are Not Alone." A discussion of impressions of the video followed.

On December 21st, the annual Holiday gathering was held. (See article on Page 3).

Education Day

Our annual Education Day was held on Friday, October 29, 2010 in the Emmaus Room at the Presbyterian Home for CNY from 9:00AM -12:00PM. Our guest speaker this year was Dr. Annie Killoran from the Movement Disorders Unit at the University of Rochester. Dr. Killoran gave a very interesting and informative presentation on the topic, "Biomarkers for Parkinson's Disease." She graciously answered questions from the audience. We thank her for taking time to come to central NY to help us better understand PD.

WELCOME!!

Several new people have joined us since October. Newcomers include Ralph and Ada Blanchard, Marge Findlay, Joe and Kathy Fresco, Ed and Marie Hill, Michael Poirier, Janice Stone and Leita Stone. We hope you will return to take part in our many activities and learn more about PD.

SMILE AWHILE!



Under the Weather?

Our best wishes go out to everyone for good health in 2011! We hope Stuart Greene, Stanley Kowalski, Charlie Mahaffey, Howard Mason, Marge Moylan, Charlie O"Hara, Michelle Thieme and Ted Wilkinson are all on the mend!

Spreading the PD Word

On November 21, 2010 our group was invited to Utica College to talk about Parkinson's disease to students in the Junior class Nursing program. Ed and Nancy McCaffrey spoke to about forty nursing students who were learning about Neurological diseases. It is such a pleasure to have the opportunity to tell the PD story to groups of young people who are anxious to learn and ask many relevant questions. We thank the Utica College staff for giving us the chance to inform more people about the disease.

World Parkinson Congress

Last fall President Pat Duciaume and Joe and Karen Leary attended the World Parkinson Congress held in Glasgow, Scotland. They will be sharing their experiences about the world PD community with our group at the March 2011 meeting. Don't miss this presentation as it will be most informative!!

Looking ahead, the Third World Congress of 2012 is planned to be held in Toronto.



CNYPSG Website Check it out!!

http://www.vtboxhwr.org/parkinson.html



Holiday Appreciation

By Sharon Lee Kelley

In your heart experience joy and peace. Focus on the brighter side so darkness will cease.

Be grateful for your many blessings Be open-minded to learn new lessons.

A challenge here – a challenge there Spend time with those of whom you deeply care.

Never hesitate to say or tell others how important they are. It can brighten up their lives – like lighting up a candle to guide them far.

Laugh often and enjoy a good joke It can lift your spirits —Don't let them be broke.

Let this holiday season flow brightly for us al With positive determination – Let's have a ball!

This is it!

By Margaret Moylan

Today is the day I relinquish the quest.
I worked long and hard, and I gave it my best.
But I can't go on banging my head against walls,
And the body can take only so many falls.
A clothing protector will cover me up,
And I'll drink my warm milk in my own sippy cup.
I'll be using my wheelchair for getting around,
And I'll try not to fall out and land on the ground.

Now if you believe every word I have writ, I will tell you straight out it's a big pile of sh__! I will never give up! I've been pulling your leg! For funding for research you'll still hear me beg. I'll do all I can and then I will do more Until with old PD I have settled the score!

Bradyphrenia

By Ed McCaffrey

Bradyphrenia makes my thought patterns slower. A reduction in dopamine, a neurotransmitter, Makes things slower and difficult to recall. Without question, it puts our backs against the wall. I pray and ask God to help find me the answers. "Please God, also include some funny stuff." I don't mind if people laugh and smile at me, If it relieves anxiety And they know my problem is PD.



In Memoriam



Betty Wollaber of Northwestern passed away on December 11, 2010. Betty was an active member of her church. She enjoyed coming to the CNYPSG picnics and special events. We extend our sympathy to her family and friends,

We also extend our thoughts and prayers to Don Hamlin and his family for the loss of his wife, Helen Hamlin, on October 22nd.

MEMORIALS

In memory of Florence Helfand

By Elliot Helfand

In Memory of William Zeiter, Jr.

by J. Gehringer
The Pearl family

In Memory of Joe & Shirley Kuba

by Jean & Temple Wilson

Donations to CNYPSG

Anthony Salvaggio

CNYPSG wishes to thank everyone for their generous contributions

NEW CPR GUIDELINES

The new guidelines may inspire more people to perform CPR, says Sayre, an associate professor of emergency medicine at Ohio State University, Columbus. "Mouth to mouth is hard if you're not trained," he tells WebMD. "Anybody can do chest compressions, whether they have had a class or not. Good chest compressions really help save lives. In many cases, there is a reserve of oxygen left in the patient's blood and lungs, from the last breath, and we can take advantage of that oxygen reserve and just do chest compressions."

How to Do the New CPR

Here is a step-by-step guide for the new CPR:

- 1. Call 911 or ask someone else to do so.
- 2. Try to get the person to respond; if he doesn't, roll the person on his or her back.
- 3. Start chest compressions. Place the heel of your hand on the center of the victim's

chest. Put your other hand on top of the first with your fingers interlaced.

- 4. Press down so you compress the chest at least 2 inches in adults and children and 1.5 inches in infants. "One hundred times a minute or even a little faster is optimal," Sayre says. (That's about the same rhythm as the beat of the Bee Gee's song "Stayin' Alive.")
- 5. If you're been trained in CPR, you can now open the airway with a head tilt and chin lift.
- 6. Pinch closed the nose of the victim. Take a normal breath, cover the victim's mouth with yours to create an airtight seal, and then give two, one-second breaths as you watch for the chest to rise.
- 7. Continue compressions and breaths -- 30 compressions, two breaths -- until help arrives.

Source: WebMD Website

NURSING HOME ADDRESSES

Marjorie Renodin

Folts Home 104 N. Washington St. Herkimer, NY 13350

Margaret Bluff

Marion Burg

James Dexter

George Fanelli

Joe Giannantelli

Stuart Greene

Barbara Grogan Victor Jarzombek

Sam Kitchen

Robert Luberda

Joan Manzelmann

Howard Mason

Nate Thomas

Presbyterian Home for CNY 4290 Middle Settlement Road New Hartford, NY 13413

Mae Mosher

VanAllen Nursing Home 755 E. Monroe St. Little Falls, NY 13365

Margaret Hoskyns

Valley Health Services 690 W. German St. Herkimer, NY13350

Betty Langdon

Eden Park Nursing Home 1800 Butterfield Ave. Utica, NY 13501

Elliott Cummins

Sitrin Health Care Center 2050 Tilden Ave. New Hartford, NY 13413

Mailing list

Please notify us if you move or want your name added or removed from our mailing list.

PLEASE CHECK ONE:

- □ Add to mailing list
- □ Delete from mailing list
- □ Change address to:

Name__

Address

Mail to: Central NY Parkinson's Support Group, Inc. 705 Ronald St. Herkimer, NY 13350

Nancy's Nonsense



The new Supermarket near our house has an automatic water mister to keep the produce fresh. Just before it goes on, you hear the sound of distant thunder and the smell of fresh rain.

When you approach the milk cases, you hear cows mooing and witness the scent of fresh hay.

When you approach the egg case, you hear hens cluck and cackle and the air is filled with the pleasing aroma of bacon and eggs frying.

The veggie department features the smell of fresh buttered corn.

I don't buy toilet paper there any more.

A little boy went up to his father and asked: "Dad, where did my intelligence come from?"

The father replied. "Well son, you must have got it from your mother, 'cause I still have mine."

A man is recovering from surgery when the Surgical Nurse appears and asks him how he is feeling.

' "I'm O. K. but I didn't like the four-letter-word the doctor used in surgery," he answered.

"What did he say," asked the nurse. "OOPS"

A wealthy man had a falling out with his two sons. It was serious enough that he decided to change his will.

At his lawyer's office, he threw his will on the table and said, "This needs an heircut."



Central New York Parkinson's Support Group, Inc. PO Box 181 New Hartford, NY 13413 Nonprofit Organization

U.S. POSTAGE

PAID

Rome, NY

Permit No. 20

Current resident or

CHECK YOUR MEETING DATES!!

JANUARY 18TH

FEBRUARY 15TH

MARCH 15TH





