



# NO PARKIN'

## **CENTRAL NEW YORK PARKINSON'S SUPPORT GROUP, Inc.**

**Vol. 17 No. 1 January 2008**  
Meeting Schedule – 3<sup>rd</sup> Tuesday – 12:30 PM  
Presbyterian Home of CNY  
4290 Middle Settlement Rd., New Hartford, NY

### **Mailing Address**

705 Ronald St.  
Herkimer, NY 13350

Phone – 866-1333  
e-mail - [glynnismoy@aol.com](mailto:glynnismoy@aol.com)

### **Board of Directors**

President -  
Patrick Moylan  
1<sup>st</sup> Vice President -  
Myrtleann Seifried  
2<sup>nd</sup> Vice President –  
Erhard Gantner  
Recording Secretary -  
Cathy Hardy  
Corresponding Secretary -  
Margaret Moylan  
Treasurer - Nancy McCaffrey

Margaret Gantner  
Barbara Grogan  
Robert Luberda  
John Matterese  
Henry Taylor

## **Calendar of Events**

**Tuesday, January 15, 2008**

**Guest speaker - Pierre Michaud**  
**Marketing Representative for Continuing Care**  
**Services @ Faxton-St. Luke's**

**Tuesday, February 19, 2008**

**Guest speaker - Maureen Roe**  
**Physical Therapist @ Presbyterian Home of CNY**

**Tuesday, March 18, 2008**

**Guest speaker - Kathleen Paciello**  
**Program Coordinator for**  
**Child lead Prevention**



**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*

Editors: Marge Moylan & Nancy McCaffrey

Production Staff: Erhard & Margaret Gantner, Barbara Grogan, Ann & Ted Lenio, John & Thea Matterese, Pat Moylan, Myrtleann Seifried, Hank & Rose Marie Taylor

### **Looking Ahead**

Happy New Year! Here's hoping that 2008 brings good times and BETTER HEALTH! Oh, do I hear some of you bah-humbugging, How can I expect better health and good times? I have Parkinson disease. It's progressive! What do I have to look forward to? Well, my friend, if you'll hang in there and keep reading, I'll try to explain.

I'm not promising a cure-all or a formula for success but rather a list of possible activities that may help. Don't overlook the obvious: good nutrition, the proper amount of exercise, and adequate rest. We all know the importance of these life activities, but do we all follow them? Not always. And don't forget that these are of equal importance to those who act as carers. Making sure you are eating a balanced diet, giving your body the sleep and exercise it needs can go a long way in making a person with PD more comfortable and allow him to feel better about himself. Remember that your vocal cords are muscles that need exercise too. Try singing, shouting, or sign up for a course in Silverman voice therapy. What a difference that can make. As far as singing goes, there actually are groups of singers in this country where the entire choir is made up of Parkinson patients. They call themselves the Tremble Clefs. If there is enough interest, maybe we could start a group right here in Central NY.

One of the best things you can do is stay with any activity that you particularly enjoy as long as you can. If it becomes too difficult or dangerous, then it must be abandoned, but try your best to come up with an alternate to take its place. One example from our group who comes to mind is CNYPSG member Walt Huegel. Walter got so he could no longer play the violin. But he didn't give up on music. He took up the euphonium (baritone horn) and formed a brass choir which entertained the support group on several occasions. Now that is making lemonade out of life's lemons.

There is one more very important item for

this list and that is ATTITUDE. Having a positive attitude can make a world of difference to a person's survival in a bad situation. Staying positive is not an easy task at best, and at times may seem impossible. It takes work, but we must focus on the abilities that remain with us rather than grieving over those lost. Look at the support group not only as a place where you can go for help but also as a place where you have the opportunity to offer a helping hand to someone else.

Margaret F. Moylan, Editor

### **ATTITUDE**

The longer I live, the more I realize the impact of attitude on life. Attitude to me is more important than facts. It is more important than the past, than education, than money, than circumstances, than failures, than successes, than what other people think or say or do. It is more important than appearance, giftedness, or skill. It will make or break a company...a church...a home...or an individual. The remarkable thing is we have a choice every day regarding the attitude we will embrace for that day. We cannot change the fact that people will act in a certain way. We cannot change the inevitable. The only thing we can do is play on the one string we have, and that is our attitude...I am convinced that life is 10% what happens to me and 90% how I react to it. And so it is with you...we are in charge of our Attitudes.

Charles Swindoll

## What Can You Do?

As an individual you can play an active role in CNYPSG. Attend meetings, make suggestions for programs, volunteer to help with social activities or the PAW fundraiser in the fall. Think about taking a seat on our Board of Directors. There are 11 seats on the Board, 3 or 4 seats to fill each year, serving 3 year terms. The Nominating Committee (Barb Grogan, chair, Margaret Gantner & Marge Moylan) will be looking for people to fill four positions before the Annual Meeting in April.

Fight back! Don't let PD get the better of you. Learn all you can about it, and then support research, financially, politically, or by taking part in a research study. (See article by Cathy Hardy p.4.) Good research takes time and seems to move so slowly, but there has been a great deal of progress since I was diagnosed with Parkinson's back in 1986. I have seen many new drugs come into use and several wonderful surgeries go from experimental to current use status. I have lost track of the number of drug studies in which I have participated in the 22 years since my diagnosis, but I am very grateful for the men and women who do the research and for the other patients who take part in the studies. I now have three new drugs in addition to Sinemet to control my disease, and I still feel like the DBS (deep brain stimulation surgery) I had done four years ago is a miracle.

Margaret F. Moylan, Editor

### UCB seeks approval of Neupro in Parkinson's Disease

Pharmaceutical Business - UCB has reported that the supplemental new drug application for the use of Neupro as adjunctive therapy with levodopa in adult patients with advanced-stage Parkinson's disease has been accepted for filing by the FDA.

The sNDA is based on efficacy and safety data in more than 670 patients with advanced-stage Parkinson's disease who were treated with rotigotine in three double-

blind, placebo-controlled clinical trials. These studies demonstrated that rotigotine, as adjunctive therapy to levodopa in patients with advanced-stage Parkinson's disease, showed clinically relevant reductions in 'off' time (periods where the effectiveness of medications wear off and Parkinson's symptoms return) and favorable increases in 'on' time without troublesome dyskinesia (fragmented or jerky movements).

The FDA has already approved Neupro for the treatment of the signs and symptoms of early-stage idiopathic Parkinson's disease and the drug has been commercially available in the United States since July 2007.

Troy Cox, president of CNS Operations, UCB, said: "We are excited that patients with all stages of Parkinson's disease may soon benefit from Neupro's 24-hour continuous drug delivery."

Source: Northwest Parkinson Foundation News

## PARKINSON'S UNITY WALK

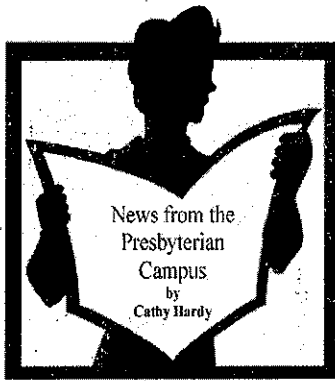
The 14<sup>th</sup> Parkinson's Unity Walk will be held on Saturday, April 26, 2008 in Manhattan's Central Park.

This is the largest grassroots fundraiser for Parkinson's research in the country. The event is not only about a beautiful 2 mile Walk in Central Park, it is about Parkinson's education for the entire family.

Where else can you talk to a neurologist or movement disorder specialist, find out about new therapies and clinical trials, locate a support group in your area and learn how to be a Parkinson's advocate— all in one place.

Join the 14<sup>th</sup> Parkinson's Unity Walk to show support for those suffering with this devastating disease.

To learn more, visit [www.unitywalk.org](http://www.unitywalk.org).



Happy New Year wishes to everyone from the residents, staff, and board members of Presbyterian Homes & Services. We look forward to another exciting and remarkable year working together with the Central New York Parkinson's Support Group. We enjoy seeing you every month at your meetings that are held on our campus.

We are currently looking for 16-20 people with Parkinson Disease to participate in "Group Medical Visits" with Drs. Biglan and Dorsey from the University of Rochester Neurology Department. We are partnering with the University of Rochester in a pioneer research study on the value of "Group Medical Visits" for those with Parkinson Disease. It will then be compared with traditional medical office visits to measure patient satisfaction. **If you are interested in participating there will be an information meeting on the research in the next couple of months at the Presbyterian Home.** We will let members of the CNYPSG know the time and date of this meeting. This is exciting news and The Presbyterian Home appreciates all of the assistance the CNYPSG has given us over the years to make projects like this possible.

Everyone enjoyed the Annual Holiday Party held on Tuesday, December 11 at PHCNY.

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**Handwriting Tip**

Handwriting can be a serious problem for persons with PD. Various pens, pencils and writing devices are available to stabilize your grip. A weighted pen may help reduce tremors and improve writing.



Lots of goodies were eaten

there was music and singing



Erin Thomas and Jessica Freeman with pianist Laureen Mitchell



Santa made a special visit with the big kids

and also with the little kids.



Does anyone know this elf that stopped by to see Santa?

\*\*\*\*\*

**Tips if Drooling is a Problem**

**When drooling is a problem, chew gum.** It helps remind you to swallow more often.

**Make it a deliberate habit to try to swallow your saliva regularly** to reduce its accumulation in your mouth. Close your lips firmly, move the saliva to the back of your throat, and swallow. Swallow any excess saliva before you speak.

Source: "Parkinson's Disease: 300 Tips for Making Life Easier"

# The Group Scoop

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## MEETING NOTES



Tiffany Voss, M.D. from the University of Rochester Medical Center was the guest speaker at our Annual Education Day held on October 17<sup>th</sup>. She gave a very informative presentation on the topic, "What's New in Research?" Dr. Voss also took time to answer many questions from the audience. Our thanks go out to her for bringing her expertise to us and the University of Rochester for their generous support!

CNYPSG members who met on November 20<sup>th</sup> had the opportunity to discuss their problems with each other. At this time, the people with Parkinson's disease and the caregivers met separately to discuss mutual problems. Many of our members find this to be very beneficial as they get to share ideas for activities of daily living.

It was Holiday Party time on December 11<sup>th</sup> and members and guests got to share in the festivities. We were delighted to have Lauren Mitchell with us again to accompany us at the piano for the singing of Christmas and Hanukkah music. She also treated us to Christmas music on the trumpet. Santa's arrival made the party complete. We also enjoyed the great food donated by the members and the drinks furnished by the Presbyterian Home. This was a great way to end 2007!

## **WELCOME!!**

What a pleasure to have several new people in attendance at recent meetings! We would like to **WELCOME** Beverly Brown, Connie Esposito, Joan Manzelmann, Debbie Olin, Annie Thomas, Lillian Town and Dorothy Ward to our group. We hope we can be of help to you and that you all will continue to join in our activities.



**CNYPSG Website  
Check it out!!**

<http://esf.uvm.edu/vtbox/parkinson.html>



## Under the Weather?

Health issues continue to plague many of the members of CNYPSG, Inc. We hope and pray that 2008 brings healthier days to Erhard and Margaret Gantner, Wilhelmina Johnson, Charlie Mahaffy, Sara Schachtler, John and Jo Schmidt, and Hank and Rose Marie Taylor and all of our group membership and friends

## M&M Shows & Health Fairs

The Moylans and the McCaffreys (also known as the M&Ms) presented their program about life with PD on October 11<sup>th</sup> at Herkimer County Community College to the Physical Therapy students. It is always a pleasure to visit colleges as the students are very attentive and ask lots of great questions. We thank the HCCC staff for giving us the opportunity to meet with them.

On November 2<sup>nd</sup> we were invited to participate in the annual Senior Services Expo at the Ava Dorfman Senior Center in Rome. Many people attend this event which gives us a great chance to distribute information about PD and our support group.

The Remsen School district invited us to take part in a health fair they held on November 30<sup>th</sup> at the school. Many students and staff were in attendance as well as community residents. This was another opportunity for us to teach area residents about life with Parkinson's disease.

Our thanks to all for inviting us to these events.

### **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**

## POETRY CORNER

### Parky's Poem

A Parky has two faces,  
One is "on" the other "off."  
I'll explain the difference  
if you promise not to scoff.  
When a Parky's on,  
It means his medicines are working.  
When he is off, the meds aren't there.  
It does not mean he's shirking.  
Parkies crawl at different speeds.  
Some can't crawl at all;  
And Parkies who walk upright  
Are apt to take a fall.  
Parky or PWP,  
Whichever term you chose,  
You better learn to laugh at yourself  
Or soon you'll be singin' the blues.  
mfm

### PD's Wild Ride

Sometimes I feel lost on a raging sea.  
Parkinson's has a bad personality.  
Like a small boat, rising up on a swell,  
When the bottom drops out,  
it's like being in Hell.

It's like being on shore  
And being caught in a tide,  
Then being sucked out to sea  
On one horrible ride.

You pray to your God  
That your medicines work and don't fail.  
Then He opens the door  
And you're released from your jail.

I can't speak for our support group.  
We're all so different, you see.  
But I'm sure there's one thing on  
which we'd all agree,  
We'd like to give back this awful P.D.

Ed McCaffrey 11/23/97

### *Making and/or using Simple Adaptive Devices at Mealtime*

If grasping and holding onto silverware is difficult, use modeling clay to build up the handles. Or take foam tubing, which comes in a variety of thicknesses, and build up the handles on utensils. Another solution is to purchase stainless steel flatware with big bamboo or plastic handles that are easier to grip. Using weighted, built-up utensils may also help decrease tremors while eating.

Use a glass or metal pie pan instead of a regular plate if you have trouble keeping food from sliding off the plate. Use a plate guard or a pasta bowl with high sides because it will be easier to get food on to the spoon or fork. Plate guards can be attached to plates to provide a rim on one side. Use your fork to push food against the guard, where food will fall onto the fork. Food guards also help reduce spills.

Place rubber pads or mats underneath plates, cups and serving dishes to keep them from sliding.

Make handling a drinking glass easier if you have hand tremors or a weakened grip:

- Fill glasses half-full.
- Wind several thick rubber bands around the glass.
- Drink from a plastic water bottle (or sports bottle) instead of a glass.
- Use a flexible plastic drinking straw instead of drinking directly out of a glass. To better hold a straw in place, find a lid of a plastic container (the same diameter as your glass), punch a hole in the lid, and insert a straw into the hole. You'll find that the straw does not slide around the glass.
- Use a child's cup with a built-in straw for drinking.
- Drink from a cup or mug that has two handles.

Source: Parkinson's Disease: 300 Tips for Making Life Easier"



## *In Memoriam*

**James L. Oberlies** of New Hartford died on October 28, 2007 at St. Elizabeth Medical Center. Jim had joined our group to learn more about Parkinson's disease after he was diagnosed with PD. We extend our sympathy to his family and friends.

**Joseph Greer** of Canastota passed away on November 3, 2007 after a lengthy battle with PD. He and his wife, Sally, were active members of CNYPSG, Inc. until failing health prevented them from participating. We send our thoughts and prayers to his family and friends.

**Carol A. Bigelow**, formerly of Oriskany, passed away on December 1, 2007 at the Martin Luther Home. She, accompanied by her husband, James, attended the CNYPSG, Inc. group meetings some time ago. Our sympathies go out to her family.

## **MEMORIALS and HONORARIUMS**

### **In Memory of Charles B. Kelly, Sr.**

by Denise Elliott  
City Court of Utica - 1<sup>st</sup> floor employees  
Michael F. Graham  
Robert & Diana Piperata  
Michael & Deborah Belmont  
Donald & Mary Wiklacz  
James E. Lehman  
Dennis Carr  
Donald E. Blanchard  
Richard Lehman  
Dave, Mary Ellen & Matt Andisik  
Patrick & Brenda Castelli  
Jerry Attili, Jr.  
Marc Bonacci  
William Mishlanie  
Rose Cariale  
Sarah Schachtler  
Stacey & Bill Paolozzi  
Evelyn Z. Petrie  
Lance & Julie Giangolini

### **In Memory of Frank Capcino**

by Emily Lewis  
Mr. & Mrs. Edward McCaffrey

### **In Memory of Kenneth T. Sutton**

by Evelyn T. Sutton  
Mort Backus & Sons, Inc.

### **In Memory of John Arcuri**

by Emily Lewis

### **In Memory of Raymond J. Lubbs**

by Donna R. Lubbs

### **In Memory of Elizabeth C. Manderano**

by JoAnne Manderano-Seccurra

### **In Memory of Shirley Kuba**

by Jean Kuba Wilson

### **In Memory of Robert W. Lorenz**

by Jim & Carol Daly  
Henry & Johanna Albrecht

### **In Memory of Carol A. Bigelow**

by Thomas & Regina Dodson

### **In Honor of Santa Claus**

by Mr. & Mrs. Patrick Moylan

## **Donations to CNYPSG**

Mr. & Mrs. John DeMartino

Evelyn Z. Petrie

**CNYPSG wishes to thank everyone for their generous contributions.**

## NURSING HOME ADDRESSES

**Margaret Bailey**  
Sunset Nursing Home  
232 Academy St.  
Boonville, NY 13309

**Helen Davis**  
Masonic Home  
2150 Bleecker St.  
Utica, NY 13501

**Joe Kuba**  
Claxton Manor -Rm. 318  
104 N. Washington St.  
Herkimer, NY 13350

**Emily Lewis**  
**Marjorie Renodin**  
Folts Home  
104 N. Washington St.  
Herkimer, NY 13350

**James Dexter**  
**George Fanelli**  
**Rod Fuess**  
**Robert Luberda**  
**Vincent Palazza**  
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

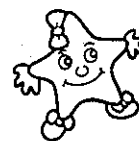
**Margaret Hoskyns**  
Valley Health Services  
690 W. German St.  
Herkimer, NY 13350

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

**Marvin Kinne**  
Heritage Health Care Center  
1657 Sunset Ave.  
Utica, NY 13502

**John DeMartino**  
**Robert McVoy**  
Sitrin Health Care Center  
2050 Tilden Ave.  
New Hartford, NY 13413

## Nancy's Nonsense



Did you hear about the guy who played golf on Christmas and accidentally hit a bird? He got a partridge on a par three.

*Source: American Legion Magazine-Dec.2007 issue*

A little boy took the chair at the barbershop.

"How would you like your hair cut today, son?" asked the barber.

"Oh, do it like you do Daddy's, with the big hole at the back."

We had just finished eating a beautiful dinner that my mother had prepared for our family. As I glanced up at the chandelier over the table, I was mesmerized by the creative handiwork a spider had woven around the prisms and light bulbs. "Don't look up there!" my mother screamed. "It's the one thing I was too tired to clean!"

"Don't look where?" my brother asked.

"There!" my mother pointed. "It's my own personal web sight!"

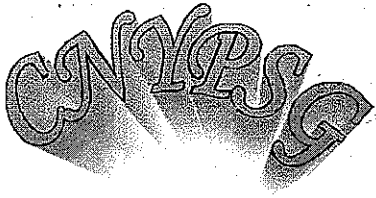
Our local newspaper ran several stories about a study that tied female obesity to a virus. One evening my sister came home exhausted from a long day at work.

"Did you read the paper?" she asked. "I'm not going in to work tomorrow. I'm calling in fat."



# Happy 2008!!





# How can we improve our support group?

Please take a moment to fill out this survey. When you're done, please send the questionnaire to:  
**CNYPSG, Inc., 705 Ronald St., Herkimer, NY 13350**

## What changes would you like to see in our meetings?

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Do you have any suggestions for programs or speakers?

- Yes
- No

Suggestions:

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Would you like a short exercise session during the meeting?

- Yes
- No

Would you be willing to serve on our Board of Directors?

- Yes
- No

Would you be interested in participating in a pioneer research study on the value of "Group Medical Visits" for those with PD? It will be held at the Presbyterian Home.

- Yes
- No

Would you like to resume our social gatherings?  
Example: Lunch or brunch on Saturday.

- Yes
- No

Would you be willing to serve on a Social Committee?

- Yes
- No

## About You (optional)

Name \_\_\_\_\_ E-mail \_\_\_\_\_  
Address \_\_\_\_\_ Phone \_\_\_\_\_  
City, State, ZIP \_\_\_\_\_  
Code \_\_\_\_\_

# HAPPY NEW YEAR!!!