



NO PARKIN'

CENTRAL NEW YORK PARKINSON'S SUPPORT GROUP, Inc.

Vol. 17 No. 3 July 2008

Meeting Schedule – 3rd 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

Board of Directors

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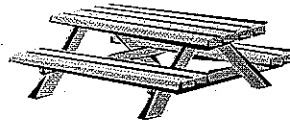
John Matterese

Calendar of Events

July 15, 2008

Park Pic #17-12:30-4:30

(details on page 4 & 10)



August 2007

No Meeting

September 6, 2008

**PAW - Parkinson Awareness Walk
at Presbyterian Home CNY – 10AM**

(details on page 6)

September 16, 2008

“Let's have lunch” (page 7)

Group discussions

Exchange of ideas-

Parkinsonians & Caregivers

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 Lenio, John & Thea Matterese, Pat Moylan, Myrtleann Seifried, Hank & Rose Marie Taylor

A Handle of Hope to Hold Onto by Margaret F. Moylan

Isn't that what all of us Parkies really need? A motivator? A reason to get up and get going in the morning? Something solid to pin our hopes to? But I guess I should be talking on a much broader scale here. We all need some kind of motivator to keep us on track. But sometimes people with Parkinson's need a little extra incentive to keep moving

I speak from experience, not from theory. I was diagnosed twenty-two years ago, with symptoms that go back at least another ten.

Over the years I have found two excellent "handles of hope" that have worked for me. The first is hope through research. I've been around long enough to have seen research ideas blossom into new drugs and treatments for PD. When I was finally diagnosed, after ten years of wondering what was wrong with me, I was put on levodopa therapy because that was the only truly effective thing they had at that time. I felt very fortunate that it was available.

The other way in which research has given me reason to hope is through my being recruited to participate in drug studies from time to time. I have never hesitated when asked to take part in one of these studies. I feel I can't lose. It may help me personally, it may help others with PD, and it will certainly add to the body of knowledge about this disease. Yes, research gives me hope.

What else gives me reason to be an optimist? My second "handle of hope" comes with the improvements that can be achieved through various kinds of therapy. There are several types of therapy which seem tailor-made for PWP (people with Parkinson's).

Physical therapy would be one. Everyone needs to exercise to keep his body in good working order. People with Parkinson's are no exception. However, we have to be careful. We have balance problems and weakness that wasn't there before. Falls come all too easily. But a

good program of physical therapy worked out with a therapist can be a lifesaver for you both physically and mentally. There is a certain sense of accomplishment in learning the exercises, then doing them each day and continuing to do them after the therapy sessions have ended.

Another useful therapy is occupational therapy which addresses problems of everyday living. When functional limitations interfere with activities such as dressing, bathing or eating, the occupational therapist can recommend the appropriate adaptive equipment. The goal here is to instruct the patient in using it efficiently and safely.

A third form of therapy which many Parkies could benefit from is voice therapy. Many of us have a lot of trouble being heard. Our voices lose volume and become almost a whisper. Again we need exercise. This time the muscles of the throat are the ones to be targeted. There is a wonderful program for PWP called the Silverman method which can have astonishing results. You work on strengthening the throat muscles and raising the volume of your voice. It begins with taking the deepest breath you can, then saying the sound "Ah" as loud as you can for as long as you can. It will amaze you how much noise you can actually make! Being able to communicate more easily can bring about a big improvement in your overall attitude. If you can focus on the positive and enjoy the things you still can do, you are on the right track. Silverman helps. These are some of the reasons I stay hopeful. Here's hoping it helps keep your hopes up!

Hope

Hope is my favorite four letter word,
Optimism radiates,
PD is on the run,
Enthusiasm bubbles to the surface.
You no longer feel like
you're under the gun.
Hope, what a glorious, jubilant word,
Wiping out **ALL NEED**

FOR SINGING THE BLUES

MFM

Common Symptoms of Parkinson's Disease

Punding and Parkinson's Disease

Punding is a human activity characterized by compulsive interest in and performance of repetitive, mechanical tasks, such as assembling and disassembling, collecting or sorting household objects. People engaging in punding find immersion in such activities comforting, even when it serves no purpose, and generally find it frustrating to be diverted from them.

In patients with Parkinson's disease, punding behaviors sometimes appear during the course of the illness. Since similar behaviors can be observed in amphetamine and cocaine abusers (often called tweaking), excessive dopaminergic tone is thought to have a prominent role in punding. Clinically, PD patients who exhibit punding often have common characteristics such as relatively younger onset, longer duration of dopamine replacement therapy, and a higher dose of dopamine or dopamine-agonists used.

Visual Hallucinations and Parkinson's Disease

Hallucinations are found in about a quarter of Parkinson's disease patients. They can occur for a variety of reasons, for example there is an overlap between Parkinson's disease and Lewy body dementia, so that where Lewy bodies are present in the visual cortex, hallucinations may result. Hallucinations can also be brought about by excessive dopaminergic stimulation. Most hallucinations are visual in nature, often formed as familiar people or animals, and are generally non-threatening in nature. Some patients find them comforting; however their caregivers often find this part of the disease the most disturbing and the occurrence of hallucinations is a major risk factor for hospitalization. Treatment options consist of modifying the dosage of dopaminergic drugs taken each day, adding an antipsychotic, or offering caregivers a psychosocial intervention to help them cope with the hallucinations. Many patients do not find the hallucinations a problem, and so do not require treatment.

Impaired Smell and Parkinson's Disease

Impaired sense of smell occurs in the earliest stages of Parkinson's disease and there is mounting evidence that it may precede motor symptoms by several years. The pathology of smell impairment in PD is not completely understood, but nerve loss is known to take place in the olfactory structures of those with the disease.

The olfactory bulb is one of two regions in the brain that receives new neurons throughout life, and dopamine depletion, which occurs in PD, has been shown to impair nerve growth in this structure in rodents. It may also be that olfactory deficits are not directly related to the structures themselves, but originate in amygdala, an area of the brain affected by PD that is known to be involved in smell function. An impaired sense of smell could also be caused by impaired sniffing, which may be another motor symptom of PD.

Source: "Parkinson Update," Spring 2008 issue.
Printed with permission of the Parkinson Foundation of the Heartland.

Walking With PD

Who's that walking down the street?
Festination in his feet
He plods along; it's his desire.
He wants you to aspire higher.

Don't be struck down by disability.
Get up and face reality.
Using muscles keeps them free,
Otherwise, they'll atrophy

Balance problems make walking bold.
Speech is muffled, swallowing problems
"old."
Bradykinesia makes movement slow
Tremor and shaking problems grow.

Muscles rigid, like in a 'rack,"
I wish I had my old ones back.
Freezing stops my motion cold,
This neurological short circuit's old.

Whoops, my medication's due
I'll take them now and I'll be through.
I'm tired now; I'll go to bed.
Sleep will swirl around my head.

**Presbyterian Home for Central New
York Telemedicine Suite for
Parkinson's Disease**

By Tony Joseph

Telemedicine can be described as the use of communication equipment to link patients and healthcare practitioners in different locations. The advantage of using this technology by providers includes:

- increased cost efficiency
- reduced transportation costs
- improved patient access to specialists
- improved quality of care
- better communication among providers.

The computer is the heart of the system. The computer handles the communications, video, data, and control aspects of the telemedicine suite. The diagnostic equipment is interfaced with the computer so readings could be automatically recorded and transmitted to the physician/physicians on the other end.

The Presbyterian Home for Central New York and the Central New York Parkinson's Support Group are currently collaborating with the Neurology Department at the University of Rochester in a research project that will measure the efficacy of telemedicine visits. These telemedicine visits will allow those residents with Parkinson's disease benefit from "medical office visits" with the U of R Neurology Department Neurologists. Without the inconvenience and expense of traveling to Rochester, remaining at the PHCNY, our residents and members of the Central New York Parkinson's Support Group are benefiting from the expertise of these nationally acclaimed neurologists.

The U of R Neurology Department is a National Center of Excellence for those with Parkinson's Disease. Drs. Biglan and Dorsey are the lead neurologists in this research project. The funds to support this project were raised by the Parkinson's Awareness Walk at the Presbyterian Home. This year's event, will take place on September 6th on the Presbyterian Home Campus.

17th Annual "Park Pic"

July is here and it's time again for our annual outing for good food, good fun and good fellowship!!

If you have never been to Pat's Picnic Pavilion, you are in for a treat! Jim is a great cook and you certainly won't go away hungry!! Of course, our CNYPSG cooks can't be beat either when they arrive with lots of dessert goodies.

Another great thing at Pat's Picnic Pavilion is their facilities can handle any kind of weather! You can sit in the sun, out of the sun or inside if it's too chilly!

It is also the day to find out who will receive the 2008 Walter H. Dickson Memorial Award for outstanding PWP (Person with Parkinson's) and outstanding Caregiver.

If you are a newcomer to our group or even have never attended any of our meetings, this is a great time to check us out! You will have a better chance to get to know us and you will see that you can still enjoy life—even with PD or other problems!!

If possible, bring a small item to be used as a Bingo prize (approx. \$2 item).

So check out the details on page 10, Bring your family and friends and join in the fun!

SEE YOU THERE!!



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**

The Group Scoop



MEETING NOTES

The Annual Meeting of CNYPSG, Inc. was held on April 15th. Members selected to serve on the Board of Directors for three-year terms were Norman Burak, Lois Greene, Ann Lenio and Myrtleann Seifried. Pat Moylan was chosen to complete the vacated two year term.

Ann Tabrizi was a very inspirational guest speaker for our May 20th meeting. Her subject was "Humor." She not only described the benefits of laughter and humor, both physical and emotional, but also taught us how to laugh. It was a pleasure to have her as our guest.

We were pleased to have Jill Petro, Clinical Research Program Manager at Slocum Dickson as our guest speaker. Jill described the process involved in becoming a part of a research program. She explained the reasons for such programs and the benefits of such projects. She also gave an overview of the research being done presently at Slocum Dickson.

WELCOME!!

Since our move to the Presbyterian Home last fall, we have been very pleased to have many new people join in our monthly activities. We wish to **WELCOME** Victor Jarzombek, Marianne Nolan, Carol Rehm and Fran Rodio who all joined us at our May meeting. We look forward to having you all continue to join us in our activities.



Under the Weather?

Many of our CNYPSG members continue to have health problems. Our thoughts and GOOD WISHES for better days go out to Erhard & Margaret Gantner, Joe Kuba, Charlie Mahaffy, Dave Schallenberg and Jo & John Schmidt.

CNYPSG, Inc. Board Meets

The Central New York Parkinson's Support Group, Inc. Board of Directors held their annual meeting on June 2, 2008. Members of the Board are Norman Burak, Lois Greene, Barbara Grogan, Ann Lenio, Howard Mason, John Matterese, Nancy McCaffrey, Pat Moylan, Myrtleann Seifried, and Hank Taylor. Officers elected for the coming year are:

President – Pat Moylan
1st Vice-president – Ann Lenio
2nd Vice-president – Hank Taylor
Recording Secretary – Myrtleann Seifried
Corresponding Secretary – Lois Greene
Treasurer – Nancy McCaffrey
Nominating Committee – Barbara Grogan - Ch., Ann Lenio & John Matterese
Finance Committee – Myrtleann Seifried - Ch., Barbara Grogan & Nancy McCaffrey

The Walter H. Dickson Memorial Awards will be presented at our annual picnic in July. Those nominated to be placed on the ballot to be voted on at the June meeting were as follows:

<u>For Parkinsonian</u>	<u>For Caregiver</u>
Sharon Kelley	Herb Freeman
Ann Lenio	Lois Greene
Fran Manley	Jim Kehoe
Howard Mason	Maureen Timerman

M&M Show

The M&Ms (Moylans and McCaffreys) were delighted to be asked to be the guest speakers at the DDSO's annual Nurse's Day program. It was held on May 1st at the Verona Fire Hall with more than 90 nurses in attendance. They were a most attentive audience and asked many great questions. They also gave us lunch and presented the CNYPSG, Inc. with a generous donation. Our thanks go out to them for giving us the opportunity to spread the word about PD.

Ted Kroll Memorial 6th Annual Parkinson's Awareness Walk

Once again we will walk the campus of the Presbyterian Home to raise awareness and funds for Parkinson's Disease. This year's honorees are Gretta & the late Donald Mitchell. Donald began his career in public service in 1954, when he became mayor of Herkimer. He moved from the mayor's office to the state assembly and then lastly was elected to congress in 1972. He retired from public life in 1983. Gretta was his partner and caregiver until his passing in 2003 caused by complications from Parkinson's disease.

**Join us on the campus of
Presbyterian Home
Saturday September 6, 2008
10 a.m.**

If you are interested in participating in the event or making a donation, please fill out the form below and return it with your check to: Presbyterian Homes & Services, Attn: Laureen Howard, P.O. Box 1144, New Hartford, NY 13413. If you would like to walk in the event, please call (315) 272-2273 or email lhoward@presbyterianhome.com and an official brochure will be sent to you. You will also be able to download the brochure from our website www.presbyterianhome.com.

Official Entry Form-Make Checks Payable to: Presbyterian Homes Foundation, Inc.	
Name _____	Address _____ City/State/ _____
Zip _____	
<input type="checkbox"/> T-Shirt Size (circle) S M L XL XXL	<input type="checkbox"/> I am interested in sponsoring the event, please forward information
	<input type="checkbox"/> I am unable to participate, but accept my enclosed contribution in the amount of \$ _____

Remember In September

Our biggest goal in September is to support the CNY Presbyterian Home in their great efforts to enhance the programs needed by the people with Parkinson's disease and other movement disorders. So far the funds raised from the Parkinson's Awareness Walk (PAW) have made it possible to get the telemedicine program, refurbish some rooms to make them Parkinson's friendly, buy teaching programs to help staff to become more familiar with the special needs of people with PD and get special PT equipment, just to name a few.

So we would like everyone to join our Support Group Team and walk the lovely mile around the Presbyterian Home campus. If you are unable to take the walk, you may support the effort by a donation or getting donations from family or friends. I'm sure Pat Moylan would love to hear from anyone who would like to join his team. For more information, check out page 6.

It has also been suggested that we gather for lunch in the Emmaus Room before our meeting in September. You can bring your lunch or buy lunch in the cafeteria. It sounds like fun and it will be a great chance to get to know each other better!

Another September event will be the Rochester PD symposium which will be held on September 20th at the Doubletree Hotel.

SUPPORT PAW!!

Join in the fun
Sept. 6, 2008



CNYPSG
Website

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

Editor's note: Thanks to Howard Mason we have the address of the PD Trials Bulletin, which provides information on both upcoming clinical trials, as well as the status of ongoing and/or completed trials.

www.pdtrials.org

Practical Tips for Living with PD

Freezing is an unpredictable loss of motion. It occurs most often during transitions such as beginning to walk, moving from carpeted area to tile, stepping into an elevator, turning a corner or approaching a chair.

Tips to overcome freezing:

- Do a side step or step backwards
- Reach forward with your heels while walking
- Count your steps out loud
- March: "left, right, left, right"
- Listen to marching tunes
- Sing (or hum) a song with a beat (a singsong rhyme will work also)
- Listen to a pocket metronome
- Visualize stepping through tall grass while walking
- Visualize a spot beyond your obstacle
- Visualize or draw an imaginary line on the floor and step over it
- Place an object on the floor (i.e. penny, paper, playing card) and step over it
- Use a pocket flashlight (or laser pointer) and step into the pool of light

PARKY GET -TOGETHER

When the Parkies get together,
it is quite the sight to see.
For we have so much in common,
yet there's vast diversity.
One will shake and quake and tremble
with such great velocity,
While another is so moveless
that a statue he could be.
You'll see dyskinesia dancing
as you've never seen before;
One might dyskinesia dance himself
right through an open door.
But as long as there are two of us,
we don't feel quite so odd
When that devil dyskinesia
declares war upon the bod.
Having folks around who understand
our clumsy awkward ways
Is one step away from Heaven
through a sunny Sinemet haze.

Margaret F. Moylan



In Memoriam

It is with great sadness we report the passing of **Sharon Fulmer** of Liverpool on May 10th. Sharon was the sister-in-law of Marge and Pat Moylan. She and her husband, Dave, have always been loyal supporters of CNYPSG and helped us with many projects. We extend our sympathy to Marge and Pat and their family.

We also send our sincere sympathy and thoughts and prayers to the Kinne family. **Mitchell Kinne**, son of CNYPSG members, Marvin and Helen Kinne, passed away on May 18th.

MEMORIALS and HONORARIUMS

In Memory of Sharon Fulmer

by Mr. & Mrs. John Schmidt
Mr. & Mrs. Edward McCaffrey

In Memory of Carl J. Conte

by Jean & Chet Potempa
Emily & John Nivaggi

In Memory of David Parmon

by Sheri Kass

In Honor of Evelyn Petrie's birthday

by Mr. & Mrs. Patrick Moylan

In Honor of Mary Wrege's birthday

by Mr. & Mrs. Patrick Moylan

Donations to CNYPSG

Sharon L. Kelley

CNY DDSO Nurse Recognition Committee

"Skip" VanDoorn

CNYPSG wishes to thank everyone for their generous contributions

"Stamp" Out Parkinson Disease

People like Michael J. Fox, Muhammad Ali, Billy Graham, and Janet Reno bring great awareness to the PD community. Think about the magnitude of awareness if we had a PD stamp designed through the U. S. Postal Service. Would you like to see a postage stamp about PD? **We would!**

It takes about 3 years to get a stamp design approved by the postal service. So this will take time. But our goal is to collect 1,000 signatures, letters, and emails from people with Parkinson's and their friends and families to submit with the new stamp request.

Add you name to our list of supporters on the www.pdstamp.org website. We will list only names & states.

This information is from the Muhammed Ali Center home page. <http://www.maprc.com/home>

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

Victor Jarzombek

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

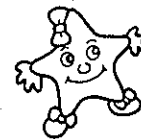
Heritage Health Care Center
1657 Sunset Ave.
Utica, NY 13502

John DeMartino

Robert McVoy

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

Nancy's Nonsense



"Mom," said the little girl, "Is it alright to say you are going to water the horse when you are giving him a drink of water?"

"Yes," said her mother, "that is the correct thing to say."

"Well then, I'm going to milk the cat."

We were thoroughly confused. While transcribing medical audiotapes, my co-worker came upon the following garbled diagnosis: "This man has pholenfrometry."

Knowing nothing about that particular condition, she double-checked with the doctor. After listening to the tape, he shook his head.

"This man," he said, translating for her, "has fallen from a tree."

A friend went to her doctor the other day, and the man was not very sympathetic with her aches and pains. "You'll just have to learn to live it," he said.

When she got her bill for \$90, she sent it back, with the notation, "You'll just have to learn to live without it!"

Joe says to Bill, "Want to see a picture of my Aunt?"

"Sure."

So Joe takes out a picture.

"What are you talking about?" Bill says, "That's not your aunt! That's a picture of a fish!"

Joe responds, "Well, sure it is... It's my aunt Chovy!"

The patient is adamant. "Doc, I need a liver transplant, a kidney transplant, a heart transplant, a cornea transplant, a spleen transplant, a pancreas transplant..."

"What on Earth makes you think you need all those?"

"Well," replied the patient, "My boss said if I want to keep my job I needed to get reorganized."

17th Annual "Park Pic"
July 15, 2008 12:30-4:30 PM

Pat's Picnic Pavilion in Rome

At the 13 Pines Motel

Cost - \$12 per person

MENU

Chicken - sausage & peppers

Baked ziti - breaded eggplant

Tossed salad - fruit salad

Soda - lemonade -

Dessert donations welcomed.

Family, friends & guests welcome!

For reservations, call

Nancy McCaffrey - 337-2467 or

Marge Moylan - 867-5770

by **July 11th**

Directions: From Utica - Take Rt.49 west. Get off at the exit for Rt. 365 (the Griffiss Industrial Park exit and sign for 13 Pines Motel). Turn right at light onto River Rd. It is about ¼ mile on the left. Turn in at sign for Pat's Picnic Pavilion. From Boonville - Take Rt. 12 south to Rt. 365 to River Rd. (flashing light). Turn right and go ¼ mile. It will be on your right. From Rome - Take East Dominick St. to River Rd. It will be on the left about 1 mile past King Pin Lanes.