NO PARKIN’ ZONE

CENTRAL NEW YORK PARKINSON’S SUPPORT GROUP, Inc.
Vol. 19  No. 3  July 2010
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
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Board of Directors
President - Pat Duciaume
1st Vice President - Henry Taylor
2nd Vice President – Rose Marie Taylor
Recording Secretary - Myrtleann Seifried
Corresponding Secretary - Lois Greene
Treasurer – Ann Lenio

Julie Dempsey
Sharon Kelley
Mary Lou Kunkel
Joe Leary
Howard Mason
Frank Russ
Joan Russ
Annie Thomas
Lillian Town
Martin Zippin

Calendar of Events

July 20, 2010
19th Annual “Park Pic” – 12:30-3:30
(details on page 2 & 10)

August 18, 2010
To be announced

September 15, 2010
Guest speaker – Tom Lorenz - Chaplin – Presbyterian Home of CNY

September 18 & 19, 2010
A Two-Day Event for Parkinson Awareness
with honored guest
Rasheda Ali

Friday Night Dinner Parkinson Awareness Walk
September 17, 2010 September 18, 2010
6:00 p.m. – 10:00 p.m. 10:00 a.m. – 12:00 p.m.
(Details on page 2 & 3)

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.
A Message from the President

You inspire me. It has been two months since I accepted the leadership of this wonderful organization. I feel so honored to be a continued part of you.

First, I would like to thank all of the outgoing officers and board members. You so graciously gave your time and talents to this organization. I am especially thankful to Pat Moylan and Nancy McCaffrey who have remained readily available to answer so many questions. In addition, I am indebted to their spouses, Marge Moylan and Ed McCaffrey who embody the “I can do it” attitude. Please extend a heartfelt thanks to the following outgoing board members: Barb Grogan, Sharon Kelley (reelected to the board), Nancy McCaffrey and Pat Moylan.

As you know, we are blessed with an energetic new and expanded board. Please take a moment to share your vision and ideas with the following board members: Julie Dempsey, Pat Duciaume, Lois Green, Sharon Kelley, Mary Lou Kunkel, Joe Leary, Ann Lenio, Howard Mason, Frank Russ, Joan Russ, Myrtleann Seifried, Hank Taylor, Rose Marie Taylor, Annie Thomas, Lillian Town and Martin Zippin.

Here is just a reminder to mark your calendar for our summer picnic slated for Tuesday, July 20th, 2010 from 1:00 P.M. – 3:30 P.M. at Preswick Glen in New Hartford. Picnic fare, games and the announcement of our Walt Dickson Award recipients for Parkinsonian of the Year and for Caregiver of the Year will be announced. Don’t miss out. Be sure to call me at 822-0032 and give your name and number in your party prior to July 12th. Tickets are $12.00 per person and payment will be received at the door. As always, homemade desserts are always welcome.

See you there! ☺
Pat Duciaume

“Let’s Knock It Out!”

What a great slogan for the events coming up on September 17th and 18th!

This year the Presbyterian Homes & Services will hold a two-day event for Parkinson Awareness. It will include a dinner to be held at Daniele’s Banquet Specialists on the 17th in honor of Rasheda Ali, world renowned author and daughter of boxer Mohammed Ali, a victim of Parkinson’s disease. Then Ali will be the Grand Marshall of the Annual Parkinson Awareness Walk (PAW) on the 18th at 10:00am on the campus. Funds raised at this event will benefit the Presbyterian Home Parkinson Renovation Project.

One of the goals of CNYPSC, Inc. is to support the Presbyterian Home in their efforts to provide the programs and services needed for people with PD and other movement disorders.

We would like everyone to join the CNYPSC, Inc. 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. More information will be provided at the annual picnic in July.

Support PAW 9-18-10
Join the CNYPSC, Inc. Team
Let’s Knock It Out!

A Two-Day Event for Parkinson Awareness

With honored guest

RASHEDA ALI

World-renowned author and
daughter of legendary boxer Muhammad Ali

Friday Night Dinner
Friday, September 17th, 2010
6:00 p.m. – 10:00 p.m.
Daniele’s Banquet Specialists
Seneca Turnpike, New Hartford, NY

Parkinson Awareness Walk
Saturday, September 18, 2010
10:00 a.m. – 12:00 p.m.
Presbyterian Homes and Services Campus
New Hartford, NY

Name ________________________________________________________________

Organization _________________________________________________________________________

Address _____________________________________________________________________________

City _______________________________________  State _______________ Zip _______________

Telephone Number ____________________________________________________________________

Sponsorship Levels

- **$2,500**
  - Eight Event Tickets to Friday Night Event
  - Full Page Ad in Friday Night Ad Book
  - Signage on Saturday-PAW Route
  - 8 Parkinson Awareness Walk T-Shirts

- **$1,500**
  - Four Event Tickets to Friday Night Event
  - Half Page Ad in Friday Night Ad Book
  - Signage on Saturday PAW Route
  - 4 Parkinson Awareness Walk T-Shirts

- **$1,000**
  - Two Tickets to Friday Night Event
  - Quarter Page Ad in Friday Night Ad Book
  - Signage on Saturday PAW route
  - 2 Parkinson Awareness Walk T-Shirts

Ad Book Sponsorship

- **$350** Back Cover
- **$250** Inside Back/Front
- **$125** Full Page
- **$ 75** Half Page
- **$ 50** Quarter Page
- **$ 25** Business Card Ad

Ticket Purchase

- **$75** Ticket Price  _____ ticket(s) to the Friday Night Dinner
- **$25** Ticket Price  _____ ticket(s) to the Saturday Parkinson Awareness Walk
- I am unable to attend but please accept my tax-deductible donation the amount of $ _____

Ticket RSVP by September 3, 2010

Please make checks payable to: Presbyterian Homes Foundation
4290 Middle Settlement Road • New Hartford, NY 13413 • (315) 272-2292

— PLEASE REMEMBER TO ATTACH YOUR AD/LOGO —
Mid-Stage Parkinson’s: Managing the Movement Symptoms

Like most aspects of Parkinson’s disease (PD), the “mid-stage” is very individualized. During this phase, symptoms become less easy to suppress using medications, and new problems, some related to PD and others provoked by the medications themselves, may develop. The term mid-stage has more to do with these changes than it does with the length of time since diagnosis. Some people experience mid-stage issues soon after diagnosis, while others may not encounter them for five or more years.

In this article, the first in a series of four, we discuss the impact that mid-stage PD has on your movement symptoms and ways you can address them.

Movement Symptoms of Mid-Stage PD

In mid-stage Parkinson’s, your medications may begin to “wear off” substantially before it’s time for the next dose, leading to “off” periods, which occur when the beneficial medication effect quickly drops off. When this happens, movement symptoms that formerly remained hidden for hours, such as tremor or stiffness, may become more troublesome than they were in earlier years.

Mid-stage often includes the onset of dyskinesias. Dyskinesias are involuntary writhing movements that are caused by dopamine medications, and tend to occur at the peak of the medication effect and taper off when the medication effect wanes. Many people experience both “on-off” fluctuations and dyskinesias: when their medications are working, they are mobile but experience dyskinesias, and when their medications wear off, dyskinesias subside, but Parkinson’s symptoms are more pronounced.

Dystonia — an often painful, sustained cramping and twisting motion — can be provoked by medication, but more likely occurs in the “off” unmedicated state. A common form is toes that curl under or upwards, often first thing in the morning.

Two additional symptoms are important to address because they can increase the risk of falls. The first is postural instability, or impaired balance and coordination. The second, freezing, happens when a person feels stuck to the ground and finds it difficult to start walking. It often occurs when a person launches forward after rising from a chair, after he or she is standing still, or while walking, in which case the body continues its forward motion, but the feet stay planted.

Tips for Managing These Symptoms

Manage Your Medications

The first step in addressing mid-stage movement symptoms is to ensure that your medications are well managed so that they last longer, symptoms are better controlled and dyskinesias are minimized. Unfortunately, postural instability and freezing do not respond to most available medications, and supplementary strategies involving physical therapy and fall prevention are needed.

The timing of medications can impact how you feel, so a key part of good management is sticking to a schedule. It is also a good idea to go through a complete list of symptoms and problems with your doctor, and to be certain about the role, dosage and timing of medications. If your symptoms fluctuate, it is helpful to keep a detailed record of your response to medications throughout the day, indicating meals, sleep and daily activities, for one week prior to your next appointment with your doctor. Some neurologists and support groups have preprinted sheets for you to use. Doctors use these reports to make informed adjustments, e.g., adding a new class of medications or adjusting the dosages or timing of them.

Work with a Physical Therapist

For postural instability, it may be helpful to work with a physical therapist (PT). With a referral from your neurologist, a PT can perform an evaluation and develop a program that may include fall prevention, balance training and the proper use of assistive devices such as canes or walkers.
Break Your “Freeze”

There are a few strategies that may help with freezing. Try marching in place until you feel the freeze breaks. Rocking side to side can also be effective. Another tip is to try singing out loud — preferably a song with a marching beat. Lastly, some people find that if they drop a string or piece of paper on the floor, and then step over it, this can break the freeze. Different tips may work at different times. So, if one doesn’t work, try another.

Seek a Second Opinion

Don’t be afraid to seek a second opinion from a movement disorder specialist (MDS), a doctor who specializes in Parkinson’s. If you are already being treated by one, another may offer fresh insight. PDF’s helpline staff — available at (800) 457-6676 — can help you locate one who is close to you, where available.

Talk to Your Doctor about DBS

When you or your loved one has tried these solutions and problems persist, it may be time to consider deep brain stimulation surgery (DBS). DBS is not for everyone, but recent research indicates that when it is done on appropriate candidates, it offers symptom control superior to that which is obtained with the best medication management. (See PDF’s booklet: Deep Brain Stimulation for PD.)

Conclusions

These are just a few ways to cope with the motor challenges of mid-stage PD. In future issues, we will examine additional aspects of the mid-stage Parkinson’s experience.

Source: The Parkinson’s Disease Foundation’s News & Review; Summer 2009

Happy Summer to all!!!

10 TIPS FOR FAMILY CAREGIVERS

1 Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
2 Watch out for signs of depression, and don’t delay in getting professional help when you need it.
3 When people offer to help, accept the offer and suggest specific things that they can do.
4 Educate yourself about your loved one’s condition and how to communicate effectively with doctors.
5 There’s a difference between caring and doing. Be open to technologies and ideas that promote your loved one’s independence.
6 Trust your instincts. Most of the time they’ll lead you in the right direction.
7 Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.
8 Grieve for your losses, and then allow yourself to dream new dreams.
9 Seek support from other caregivers. There is great strength in knowing you are not alone.
10 Stand up for your rights as a caregiver and a citizen.

Are You Getting Enough D?

You may have heard that Vitamin D is important to maintain strong bones and muscles. It may also help prevent heart disease and some cancer.

Yet many older adults don’t get enough of the vitamin in their diets to meet recommended daily needs: 400 international units (IU) from ages 51 to 70; 600 IU starting at 71.

The best food sources of vitamin D are salmon, tuna, mackerel and sardines. Next best are fortified foods, such as orange juice, milk, yogurt, margarine and ready-to-eat cereals. Check product labels before buying to see if vitamin D has been added.

A blood test can tell whether you are getting enough vitamin D. If not, your doctor may want you to take a supplement.

Source: National Institutes of Health
MEETING NOTES

President Pat Moylan presided at the CNYPSG, Inc. annual meeting held on April 20, 2010. A motion was made to enlarge the Board of Directors to 16 members and the motion was approved. The membership voted for ten people to fill the vacant seats on the Board. Following the selection of Board members, the people with PD and the caregivers met as separate groups to share and discuss mutual interests and problems.

Our new President, Pat Duciaume, presided at the May 18th meeting. Pat shared some of her hopes and ideas for the coming year and asked for the membership’s help and cooperation. The M&M show featuring the Moylans and the McCaffreys was the program for the day. Then time was allotted for the people with PD and the caregivers to meet for group discussions.

At our June 15th meeting, Emily Levitt spoke to us about “Disaster Preparedness.” She presented vital information about the things that are needed in an emergency of any kind (storm, flood, fire or anything). She gave us insight into how she had prepared her own family and included such things as emergency numbers, medical records, water, food and other things. We thank her for sharing her expertise in how to be ready for difficult times. For more information, call the Citizen Corp at 223-3279.

WELCOME!!

How nice it is to have new people join us at nearly every meeting!! In April, Phil Marmelstein and Janet Isabelle joined us. Newcomers in May were Fred Bangs and Charles and Audrey Salzman. Nancy Bangs came along with Fred to our June gathering. A special “WELCOME” to you all and we hope you will join in our future activities!

CNYP SG, Inc. Board of Directors Meets

The new Board of Directors for CNYP SG, Inc. held their annual meeting on May 24, 2010. The now sixteen member board includes many new people and some old faithfuls (named in the President’s message on page 2)

Officers selected for the coming year are:

President – Pat Duciaume
1st Vice-president – Hank Taylor
2nd Vice-president – Rose Marie Taylor
Recording Secretary – Myrtleann Seifried
Corresponding Secretary – Lois Greene
Treasurer – Ann Lenio

The Walter H. Dickson Memorial Awards were voted on at the June meeting and will be presented at our annual picnic in July.

These awards are given in memory of Walt Dickson who played a major role in the formation of the Central NY Parkinson’s Support Group in 1992. Walt was church liaison for the New Hartford Methodist Church where we met for our first 15 years of existence.

Nominees for this year are:
For Parkinsonian For Caregiver
Victor Jarzombek Esther Kitchen
Sam Kitchen Frank Russ
Howard Mason Kerry Thieme
Joan Russ Annie Thomas

Summer has arrived and we hope all of our members and friends who have been ill or need to heal are improving! Our best wishes for healthier days go out to Elliott Cummins, Barbara Grogan, Wally Kellogg, Charlie Mahaffy, Charles O’Hara, John Schmidt, Alan Silver and Elmer and Lucy Washburn.
HEALTH FAIRS

Myrtleann Seifried attended the Health and Fitness Expo in honor of National Senior Health & Fitness Day on May 26th at Edward A. Hannah Parkway Community Center in Utica. This was another opportunity to get information about PD and movement disorders to the public. We thank Myrtleann for volunteering to represent our Support Group.

CNYPSG, Inc. will be participating in the Boonville-Oneida County Fair’s Community Health Festival Day on Wednesday, July 28, 2010. This will be another great chance to let everyone know that our support group is open to the public for support and information! We welcome any volunteers for that day!

Support for Caregivers

The Oneida County Office of the Aging sponsors a Caregivers Support Group which is open to the public. This group meets on the first Wednesday of every month at 6:30 p.m. to 8:30 p.m. at the North Utica Community Center, 50 Riverside Drive in Utica. For more information, call Michelle Murphy at the Office of the Aging - 723-6233.

Rochester Symposium; 2010
Managing PD

The Rochester Support Group will host their 21st PD Symposium on Saturday September 25, 2010. Featuring speakers from the University of Rochester’s Memory and Inherited Neurological Disorders (MIND) unit, they will be focusing on the latest research, new drug trials, complementary medicines such as Tai Chi and ballroom dancing, and hearing from physicians who oversee and perform deep brain stimulation surgery as well as the patients who have undergone the procedure.

For more information, call 585-234-5355 or go to www.PSGUNY.ORG

Embrace Life Fully
By Sharon Lee Kelley

Be like the flowers – bloom and grow
Be open minded so greater understanding will flow.

Shine like the sun
Make each day a wonderful one.

Be like the moon; reflect the light
With difficult challenge – never give up the fight.

Give thanks to God in heaven above
Share kindness and laughter along with love.

Blessings

Blessings come in strange disguises
Life is to be lived
Greet new challenges
with open arms.

Disability
Does not mean I can't,
Merely that I search
until I find new avenues.
Margaret F. Moylan

Diagnosis PD

Parkinson’s disease has
No known cause, no known cure;
No X-rays, scans or lab work
For research to open the door.

To make a diagnosis, your doctor relies
On objective symptoms that he sees with his eyes.
The subjective ones are important too,
The ones you tell him are bothering you.

The most conclusive things the doctor sees
Are tremor, slow movement, rigidity.
Balance problems and the “freeze”
With motor control problems that put you down on your knees.

By the time you’re diagnosed PD
You have a dopamine deficit of 70-80% you see.
To resolve this, Sinemet and/or an agonist must be added too.
This helps repair the synapses so the messages get through.

The body responds to the brain’s call
And the basal ganglion is back on the ball.
Ed McCaffrey
In Memoriam

Roderick L. Fuess of New Hartford passed away on April 10, 2010 at the Presbyterian Home for Central NY. He and his wife, Elsie, were former residents of Oriskany Falls where he was an active member of his community and church. Rod and Elsie were noted for being beautiful ballroom dancers. We extend our sincere sympathy to his family and friends.

HONORARIUMS

In Honor of Baden Mudge’s 85th Birthday

by Mr. & Mrs. Patrick Moylan
Evelyn Petrie & family
Mary & Paul Wrege & family
Esther Miller & family

CNYSYG wishes to thank everyone for their generous contributions

CNYSYG TRIVIA

By Marge Moylan

“LOOKING BACK”

The Central New York Parkinson Support Group has quite a history. To some of you newer members it may seem like ancient history. We have been around for 18 years. I'll give you one for free. The first meeting of the group was held in January 1992. Come on and play. You might learn something, and it could be fun!

(All answers will appear at the bottom of the page)

Question 1
Who was the member that named our newsletter "No Parkin’ Zone"?

Question 2
How many presidents have led CNYSYG?
  Bonus question
  Can you name them?
  Super Bonus
  Can you give their dates in office?

Question 3
Since the group was founded in 1992, there have been 2 permanent meeting locations. What are they?

Question 4
Officers elected for 1994 - 95 were:
  President - Marge Moylan
  1st VP - Evelyn Petrie
  2nd VP - Elizabeth Brewer
  Recording Secretary - Kay Austin
  Corresponding Secretary - Shirley Kuba
  Treasurer – Bob Luberda

What was the "unofficial" nickname of this group?

Question 5
The first issue of "No Parkin’ Zone went out in July, 1992. How much do you think we spent on printing and postage a) less than $10  b) more than $16 but less than $29  c) $42  d) more than $50

Question 6
What CNYSYG member coined the phrase “Parkinsonians on the Move” both to describe the attitude of the group and his wife’s dyskinesia?

Answers:
1. Tom O'Donnell
2. 4 Presidents – Gordon Jeffrey 92-94, Marge Moylan ’94-’97, Pat Moylan ’97-’10, Pat Duciaume
3. New Hartford Methodist Church & Presbyterian Home
4. Bob’s Harem
5. b
6. Bob Davis
NURSING HOME ADDRESSES

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

Marion Burg
James Dexter
George Fanelli
Joe Giannantelli
Victor Jarzombek
Sam Kitchen
Robert Lubarda
Joan Manzelmann
Vincent Palazza
Nate Thomas
Ted Wilkinson
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

Elliott Cummins
John DeMartino
Sitrin Health Care Center
2050 Tilden Ave.
New Hartford, NY 13413

My wife, a real estate agent, wrote an ad for a house she was listing. The house had a second-floor suite that could be accessed using a lift chair that slid along the staircase.

Quickly describing this feature, she inadvertently made it sound even more attractive: "Mother-in-law suite comes with an electric chair."

Soon after we were married, my husband, Paul, stopped wearing his wedding band.

"Why don't you ever wear your ring?" I asked.

"It cuts off my circulation," Paul replied.

"I know," I said. "It's supposed to."

At the beginning of the school year, one seventh grader was reflecting on his chance at being the 8th grade valedictorian. He said his dad was valedictorian, his mom was valedictorian, and his sister was also valedictorian. He paused, leaned back in his chair and said, "Looks like the end of an era!"

Fellow employees at the international company where I work know I'm a notary public and have me certify personal documents.

One day, two Swedish men asked me to witness signatures on an automobile title. "I'm selling my car to this man," one of them explained. "We came here because we heard you were notorious."

CNYPSG Website
Check it out!!

http://www.vtboxhwr.org/parkinson.html
Current resident or

19th Annual “Park Pic”
July 20, 2010  12:30-3:30 PM
Preswick Glen
55 Preswick Drive, New Hartford
Cost - $12 per person

MENU
Grilled chicken – eggplant/tomato sauce
Bow tie pasta – corn on the cob
Tossed salad – fruit platter
Coffee - tea
Dessert donations welcomed

Family, friends & guests welcome!
For reservations, call
Pat Duciaume – 272-2267 or
822-0032
by July 11th

x – Presbyterian Home
star – Preswick Glen