

CENTRAL NEW YORK PARKINSON'S SUPPORT GROUP, Inc.

Tremor's Group Volume 1 No. 1 June 2012 Editor: Don Hamlin

Meeting Schedule – 3rd Tuesday – 12:30 PM Presbyterian Home of CNY – Emmaus Room 4290 Middle Settlement Rd., New Hartford, NY 13413

Mailing Address

P.O. Box 274 New Hartford, NY 13413

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Board of Directors

President -Rose Marie Taylor 1st Vice President -Marty Zippin Recording Secretary -**Annie Thomas** Corresponding Secretary -Deanna Ventura Treasurer -Myrtleann Seifried Editor: Don Hamlin **Sharon Kelley** Joe Leary Howard Mason Julia Sainz

Lillian Town

Calendar of Events

Oneida County

June 19, 2012
Topic:
Speaker: Dr. Michael Cuda
Anesthesiologist

July 17, 2012
Annual Picnic
Preswick Glen
Cost: \$12:00
12:30 meet and greet
1:00 Lunch

June
Executive Board
will meet the
1st Wednesday of
every month

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.



Tribute and Honor Page

In each edition, we will honor a person or persons who have done or are still doing outstanding service to the Central New York Parkinson's Group.

In this edition, we honor Nancy
McCaffery. Nancy has been an active
member of this group for many years and
contributed her time and talent in many
ways. We especially want to thank her for
all that she has done as editor of this
newsletter.

For a number of years Nancy served as assistant to Marge Moylan, the previous editor. Nancy learned well from Marge and made a smooth transition to editor when Marge had to leave the position due to health issues.

For the past years as editor, Nancy has produced a first class newsletter to keep all of the members well informed and entertained. At this point, the person assuming the position usually says: "I know that I could never fill Nancy's

shoes, etc." However, I am not going to say that. When you see Nancy's tiny feet and my clod hoppers, that statement would seem very much out of place. Besides this is not a contest or comparison. Each person has his/her own style and vision.

When I leave this position I hope that folks will say something like I now say to Nancy:

"I thank you Nancy McCaffery for a job well done. Enjoy some time to yourself. But, please send us an article once in a while especially the recipe for your famous RUM CAKE. We will include the recipe annually in our December issue.

Welcome to the Board of Directors

Congratulations to our newly elected President and the Board of Directors. I also wish to thank each member for accepting their positions. This is an active Board and it is time to restructure. Strong leadership is needed and with this Election of these members, we have an excellent Board.

A boy came home from school all excited and told his father that he had a part in the school play. "What role are you playing?" asked the father. "I am going to be a man who has been married for 45 years." Said the boy. The father said "If you do a good job in this play, next year they may give you a speaking role."

Message from the President

I accepted this position because I wanted to do my part in helping this organization. I have never held an executive position before and have concerns about my ability to do things properly. However, since accepting the presidency, I have received so much help from those on the executive committee I feel I much more confidence now. I want to thank everyone for all of the help they have given me and I am sure will continue to give me.

We have a lot of work to do and everyone gives freely of their time and energy. What a wonderful group!! I would also invite every member of this organization to contact me with any advice, suggestions or questions. My phone numbers are 732-6302 (H) and 790-4606.

I am sure that with everyone working together we will enjoy another great year. Sincerely, Rose Marie Taylor

WELCOME

We have been blessed to have many new people continue to join us to find out more about Parkinson's disease and other Movement Disorders. Let us strive to have more people join our group so that we are able to help people understand the many problems faced by people with these afflictions and help them cope with their difficulties. *Please join us* regularly at our meetings and let us know how we can assist you. Become involved in our group activities throughout 2012!



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

Under the Weather?

2012 has arrived and we are wishing all have recuperated and everyone will have a year of good health. We hope that Howie Mason, Charley MaHaffy, Ann Lenio, Charley O'Hara and Cindy Joseph are enjoying healthier times. We look forward to having you join us!

In Memorium

For those who are deceased, let them rest in peace.

Gordon Donahue, Jo Grogan, R.N., John Schmidt, Joan Manzelman, Bob Luberda, Louise Caruso, Sam Kitchen, Joe Giannatelli, Helen Seyse, Wilemina (Willy) Johnson, Jim Dexter, Charles Salzman, David Timmerman.

NURSING HOME ADDRESSES

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

Margaret Bluff
Stuart Greene
Barbara Grogan
Victor Jarzombek
Hank Taylor
Nate Thomas
Presbyterian Home for CNY
4290 Middle Settlement Road
New Hartford, NY 13413

Mae Mosher
Van Allen 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

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. P.O. Box 274 New Hartford, NY 13413



By Pat Moylan

On April 18th, 2012, CNYPSG held its annual education day at the Presbyterian Home as part of Parkinson's Awareness Month. We had approximately 75 persons in attendance and the featured speaker was Dr. Kevin Biglan from the movement disorder unit at the University of Rochester.

Dr. Biglan gave a very interesting and informative talk about the telemedicine project that is now into its' fifth year and the Home at he explained the many benefits for the participants. He mentioned how telemedicine begun to revolutionize the patient-doctor relationship and how it can be used in the home environment as well. During and after the presentation there were many questions and D Biglan addressed them all. This is the third tim Dr. Biglan has spoken to our group over the last several years, including 2000 and 2007. The group is gratified by both the Home and the Dr.'s commitment to telemedicine. We continue

Dr.'s commitment to telemedicine. We continue to look forward to innovative research in this field and we thank the Dr. for taking time from his busy schedule to share his expertise with u

Good News!

From Marge and Pat Moylan

With this issue of "No Parkin' Zone", now into its 20th year, the CNYPSG extends an enthusiastic and grateful "WELCOME ABOAI to our new editor, Don Hamlin. Don comes well qualified for thi position, having taught English in Clinton for 30 years. A support group member for the last few years, Don has also served a term

the Board of Directors.

No Parkin' Zone Staff

Editor: Don Hamlin

Contributors: Sharon Kelley, Joe Leary, Margaret Moylan

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

Letter from the Editor

Parkinson's disease is a difficult disease to understand. We do not know what causes it but we do know that there is no known cure. Each person who has this disease will have unique experiences as to when they became aware that they had Parkinson's, how it progressed, etc.

I would like to share my history with you.

I do not know exactly how old I was when I first became aware that something was not right with my balance and muscle control. I taught English to high school juniors and seniors for thirty years. I also had a house painting business during the summer and I was an active basketball official for 55 years. During all those years of rushing up and down ladders and racing around basketball courts, I never experienced any symptoms. On my 69th birthday I was working on the roof of Babe's restaurant so I must have been in my early 70's when I noticed the onset.

My mother was one of 17 and my father one of nine. One of my mother's brothers died from a severe case of Parkinson's and one of his son's did the same. There has been no other family history of Parkinson's until my outbreak.

I did therapy treatments and voice therapy here at the home and it did help except for balance. For the past several years I have had good control and could walk without a cane or any other support. However, in the last two to three months I have noticed a great acceleration in my lack of motor control. I now have great difficulty in standing and walking and I find it necessary to use my walker when I am away from home and my scooter when I am home. Their also has been rapid loss of my eyesight and my speech. My hands have also become almost useless but I think my arthritis is the main cause of that.

It will be interesting for me to see if this will continue to be rapid or if it will reach a level and keep that way for a while.

I will keep you informed but you will also be able to observe any change in my condition.

Don Hamlin

Aggressive Drivers are the ones who try to get back at you after you cut them off.

Values and Learnings of the CNYPSG

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By Sharon Lee Kelley

The Central New York Parkinson's Support Group is made up of remarkable, extraordinary human beings filled with courage, compassion caring and sharing.

Upon attending the group, I've witnessed Outstanding courage by so many-those in various stages of the disease-often with additional health problems. Many people with Parkinson's disease or other movement disorders who attend the support group shine their light so bright they uplift others by focusing on the positive and counting their many blessings. Our CNY group with Parkinson's and people with other movement disorders are cohesive.

Together we care and share By encouraging one another Our burdens are easier to bear. Laugh a lot and use humor often. Get those endorphins a pumping So pain and hardships soften. When one is feeling down, a joke is a good time to tell Lots of laughter and you'll soon feel more well In the support group we teach and reach We make suggestions, share experiences Yet never try to preach. Keep hope in your heart Provide the spark To jog one another's mind In search for a cure we hope to find.

Discover new techniques and treatments

To help us out of our bind

Find new ways of improving the quality of life And living with the disease To benefit all mankind

Letter to the Editor in the Observer Dispatch 4-13-12 Edition From Joseph A Leary/Westmorland Joseph wrote:

Those who suffer from Parkinson's can get support

April is Parkinson's Disease Awareness month. Parkinson's is a neurological movement disorder. It is a chronic, progressive and debilitating disease that gradually robs a person of the ability to control their own body movements. The longer you have it, the worse it gets. There is also no cure. Eventually it will affect everything you do 24/7.

It is estimated that 1 million people in the United States have the disease, and 50,000 new cases are diagnosed each year.

Although most of the cases of the disease occur with people over 50 years of age, there are more and more people who are diagnosed in their early thirties.

Treatment involves symptom management. The early motor symptoms are:

Tremor or uncontrolled shaking, rigidity due to opposing muscle groups in constant contraction, Bradykinesia or slow movement, Festination-the rapid shuffling of the feet in short steps and a forward stooped posture.

Initially these symptoms can be managed quite well for a few years with drugs and physical therapy. However, as the disease progresses, you get less relief from the same doses of medication. At this point the drugs can cause problems of their own.

The CNY Parkinson's Support Group (CNYPSG) meets the third Tuesday of the month at the Presbyterian Home on Middle Settlement Road in New Hartford a 1 p.m. We have a variety of programs scheduled throughout the year. Meetings are free and open to anyone.

(In April we had donation canisters out at many locations.)

7 Special offer

Don will donate \$5.00 to the Parkinson's Support Group for every book purchased or sold by any member of our group.

Please fill out the order form below and send it in now. The total cost for the book is \$20.00 and an additional \$5.00 if mailing is required.

No payment has to be made at this time but can be made at your convenience. If it is possible to send the \$5.00 to cover the donation with the order, it would help, but it is not necessary. The balance can be paid as your budget allows: \$5.00/mo., \$5.00 year, \$1.00 mo., \$1.00 year . . . this one might put a little pressure on some of our longevity clocks.

My point is- I did not write this book to make money. I wrote it to honor my late wife, Helen, and as my legacy-to continue to make people laugh, be happy and feel good about themselves, even after I am gone.

My strong desire is for every member of our group to help me to achieve my goal by ordering a personal copy of my book at this time.

This offer also extends into the future-the book makes a wonderful

gift-for birthdays, gifts or any occasion.

Orders sent should have a "P" marked on the order form so that a donation will be made.

Most of the members receiving this newsletter are unable to attend the monthly meetings. The newsletter is sent to keep everyone informed and up to date. Your support of this book offer will help us raise the funds to meet our expenses.

Thank you!

Order Form "P"

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Any questions, call 853-2396 or 868-4792

Clinton, NY 13323