



NO PARKIN' ZONE

CENTRAL NEW YORK PARKINSON'S SUPPORT GROUP, Inc.

Vol. 20 No. 2 April 2011

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

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Board of Directors

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Joan Russ
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Annie Thomas
Lillian Town
Martin Zippin

Calendar of Events

April 19, 2011

Annual Meeting

Guest Speaker – Jack Rockwell

Co-owner of “Seniors Helping Seniors”

May 14, 2011 – 7:00 P.M.

Benefit Concert featuring

Dr. Joe Utterback – Jazz Pianist

First Presbyterian Church, Genesee St. , Utica

May 17, 2011

Live Auction – Bake Sale

White Elephant Sale – Benefit of CNYPSG

June 21, 2011

**“Medical Massage Therapy
for Parkinsonians”**

Presented by Audrey Woodard

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

Contributors: Sharon Kelley, Joe Leary, Margaret Moylan

Production Staff: Stuart & Lois Greene, Barbara Grogan, Ann Lenio, John & Thea Matteredese, Pat Moylan, Myrtleann Seifried, Hank & Rose Marie Taylor

A Message from the President

March came and went at a record pace. We have waited a very long time for spring and it is finally here!

Many things are underway. By the time you read this, the nominating committee (Sharon Kelly, Chair, Joe Leary and Marty Zippin) will have completed their work to fill 5 vacant seats on the board. I would like to extend a heartfelt thanks to outgoing board members: Lois Greene (Corresponding Secretary), Anne Lenio (Treasurer), Frank Russ, Joan Russ and Myrtle Anne Seifried. Presentation of a slate and election of officers and board members will occur at our April general membership meeting.

Thanks to the generosity and talents of Tom Lorenz, Chaplain, Audrey Woodard, Licensed Massage Therapist and Joe Leary, CNYPSG, Inc board member we have benefited from three wonderful programs. Our January program brought thought to "The Journey of Loss". In February, our program allowed group participation in "The Healing Power of Yoga". And lastly, our March program brought you up close and personal to a memorable recap of the 2nd World Parkinson's Congress in Glasgow, Scotland.

As part of April is Parkinson's disease month, numerous members are contacting local merchants and making labeled clear donation jars available to them to gain attention to Parkinson's disease and to obtain much needed funds for our support group. In addition, several educational presentations will be available in the reception area of the Presbyterian Home. Here is your chance to buddy up and serve as a helper in these get out the word opportunities.

The SUNY IT Health Fair on April 12th kicks off our efforts to educate and assist members in our community regarding Parkinson's disease. I owe a special thanks to our dedicated duo Myrtle Anne Seifried and Joe Leary (and everyone else) who graciously donates their time and efforts in this worthwhile cause.

Mark your calendar for Jack Rockwell, co-owner of "Seniors Helping Seniors", an organization that pairs much needed caregivers with others requiring help at home. He will talk and utilize a power point presentation on Tuesday, April 19th, 2011 at 1:30 P.M. in the Emmaus room at the Presbyterian Home in New Hartford, N.Y.

May promises to be an extraordinarily busy month with the much awaited benefit concert by Dr. Joe Utterback, renowned jazz pianist on Saturday, May 14th, 2011 at 7:00P.M. at the First Presbyterian Church on Genesee Street in Utica.

Please help spread the word and participate in selling advance sale tickets to benefit the renovation project in the movement disorders wing at the Presbyterian Home..

Last but assuredly not least, be prepared for a whirlwind opportunity to participate in a live auction of gently used "as is" medical equipment, a white elephant sale and a spectacular bake sale to benefit our coffers on May 17th at 1:00 P.M. .

Let me close with "So much to do . . . so little time". Please lend a hand.

Pat Duciaume, President

Dear CNYPSG friends,

Our sincere thanks to all for the many acts of kindness and expressions of sympathy that were extended to us at the time of Ed's death.

They will always be remembered..

Nancy McCaffrey and family



Keeping a Journal

Here's some advice primarily for the newly diagnosed people with Parkinson's (PWP), although it could benefit all of us I would think. I was diagnosed with Parkinson's disease in April of 2004. Now there's irony for ya because April is PD awareness month. When I came upon the first anniversary of my diagnosis, I sat down and made a short list of the activities that gave me problems due to the PD, like buttoning my shirt or tying my shoes. I also made a short list of what good and bad days were like and how the meds I was taking affected my activities. The original reasoning for these notes was so that I had something to show my neurologist what was going on. I also noticed that after I put these thoughts to paper, I felt just a little better.

Well my neurologist liked the idea of the notes because it gave him a better understanding of how things were going with my therapy between visits. The notes would become a regular part of my continuing visits. A better understanding of the situation leads to better, more informed treatment and it shows the doctor that I am very involved with the treatment of my PD.

It's been 6 1/2 years now since diagnosis and my journal is still an integral part of my Parkinson's management. At this writing it is at 55 pages and 252 dated entries. I don't write in it everyday. I try to keep it to a few notes a month unless I'm on some new medicine or I'm traveling. I pay particular attention to the dates, times, and dosages of my meds, how I react to them, and how long I'm "on" or "off". I note good days as well as bad days. As more good days or bad days are noted in a certain time frame you will have an indicator of how the PD is progressing or not. The journal also helped me get early approval for my SSDI benefits and showed my health insurance carrier that I was a candidate for DBS surgery, when used as a supplement to my doctor's notes.

Not sure you can be that disciplined to keep current with a journal? Then I suggest you give it a try for a season of the year. A day, a week, or even a month is too short a time frame to develop a rhythm to your writing..

You don't have to write like Mark Twain or J.K. Rowling, but you should be bluntly honest in your writing, If your "off" times are really bad or the dyskinesias are not easily controlled, say so in your writing. Also if things are "going pretty good, couldn't be better, thank you very much," say so in your writing. Then if you bring these notes with you to your next neurologist visit, he/she will have a better idea of how to attack these problems.

Keeping a journal is not for everybody. It does require some discipline, but it is no more than the same discipline you use to take your meds everyday. It requires that you be truthful with yourself and how you feel . The only way to find out if it works for you is to try it. Be careful though as you just might surprise yourself with it and how it can help you through your daily battle against Parkinson's Disease. .

by Joseph A. Leary
Dx – PD 04/04

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 attempt to speak.



Pain or PD Related Pain?

By Peggy Willocks

A frequently asked question, "Is there any pain with Parkinson's disease (PD)?" is seldom properly addressed. The answer is both "yes" and "no." Not everyone experiences pain related to PD, but for those who do, the pain is very real. Left untreated, PD-related pain can cause symptoms to fluctuate and at times actually worsen. While I am not a professional specializing in diagnosing or treating pain associated with Parkinson's, I do hold expertise by virtue of living 17+ years with this neurological illness (diagnosed at age 44 with symptoms as early as my late 30's). I also have chronic pain, much of it attributable to the PD symptoms or medication side effects. Having some understanding of PD-related pain and working with your doctor to determine appropriate treatment options can help to greatly improve your quality of life.

Many doctors are either unaware of or fail to acknowledge the relationship of pain to PD, causing undue suffering. Pain experienced with PD is difficult to pinpoint, with patients often reporting that they "hurt all over." Failure to locate and assess the source of pain makes therapy choices even more ambiguous. Untreated pain can lead to more serious complications, to include sleep deprivation and depression.

It is likely that there are more cases of untreated PD-related pain than you might think, and it can be both debilitating and devastating. Pain is the body's "warning system" that it's time for a check-up. Ignoring such signals might result in more serious complications which can and WILL play havoc with emotions and mental well-being

APDA would like to explore this topic of PD-related pain further, and you can help. Complete our brief survey, [Pain & Parkinson's](#), online. This is not a research-based survey; it is for informational purposes only. Pooling our first-hand

experiences of PD-related pain will help us better understand it. Even more important, if quality of life can be improved by treating PD-related pain, then that should be our goal.



**Pay
Attention
To Pain**

I reported to my family doctor that I was having pain and numbness in my hands and arms. The doctor wrote it off as carpal tunnel syndrome and told me I could have "a simple outpatient procedure" done when I felt I could no longer tolerate the pain. When the symptoms grew more intense, adding severe neck pain, it sent me calling on the services of a neurosurgeon. The doctor discovered herniations of my cervical spine (neck), likely due to severe dyskinesias resulting from long-term L-dopa therapy. Over the last three years, two cervical fusions had to be done to relieve the arm pain. Had those surgeries not been done, I was told, a fall may have been fatal. - Peggy

Peggy Willocks is a former elementary school principal, State Coordinator (TN) and Board member for PAN, and recipient of the Millie Kondrake Award for Outstanding Advocacy. In 2000, Peggy underwent experimental brain surgery. She presented at the 2006 World Parkinson Congress and in 2010 was part of a national webcast for Clinical Research Educator Day.

"Reprinted with permission from the APDA Young Parkinson's Newsletter; author, Peggy Willocks."



A Man Who Made a Difference

By Margaret R. Moylan

Edward A. McCaffrey passed away peacefully at home, on Monday, February 28th after a long struggle with Parkinson's disease. He has gone to a well deserved rest.

Yes, Ed was one of those people who made a difference. The large turnout of family and friends for the calling hours and funeral can attest to that difference. The funeral mass became a celebration of Ed's life. Ed was always ready to lend a helping hand, with a ready smile and a joke to tell. When Parkinson's disease struck, Ed was not one to sit at home feeling sorry for himself. He kept going, letting people see what could be accomplished even with PD. For example, for the first Parkinson's Awareness Walk (PAW) at the Presbyterian Home, Ed and I dressed as clowns and drove our motorized carts for the walk. That went so well, we did it again in the Iliion DooDah Parade. Anything to promote visibility for PD! Another time, Ed and Nancy, Pat and I, took the train to New York City along with some folks from the Rochester Support Group to take part in the Parkinson Unity Walk. We were rewarded with visibility when the next issue of the National Parkinson Foundation newsletter came out and had in it a photo of us carrying the CNYPSG banner during the walk. When the walk was over, Ed and I celebrated the event by dancing in Central Park with our walkers. Another activity to raise PD awareness was the M & M Road Show. The four of us traveled all over central New York educating the community about Parkinson's disease. I think having two of the speakers being PD patients made it more meaningful for our audiences.

Ed McCaffrey was my good friend and fellow 'Parkie Poet.' The folksy, down-home style of Ed's poetry was an inspiration to many PWP's and caregivers. Ed believed that laughter was the best medicine, and you have to learn to laugh at yourself. Ed was a master of that! He will be missed.

GROUP NEWS

WELCOME!!

It is so gratifying to see the attendance at our Support Group meetings continue to grow. Once again we are pleased to say, "WELCOME", to our recent newcomers, Ron and Lucy Alpert and John and Gail Walrath. We look forward to having you participate in our many activities in the coming year!



Under the Weather?

Spring is here and we hope all the winter ills left with the winter cold and snow! It is our hope that Stuart Greene, Sharon Kelley, Joe Leary, Charlie Mahaffy, Howard Mason, Baden Mudge and all of our members are healthy and able to enjoy the pleasures of spring!



CNYPSG Website
Check it out!!

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

Parkinson's Awareness Month

April is designated again as Parkinson's Awareness Month and CNYPSG has always been ready and able to help people understand more about PD. As in the past, our members will be participating in local health fairs to help spread the word! April 12th is the SUNY IT Health Fair and the May 25th fair will be at the Ed Hanna Parkway Center.

In honor of this special occasion, the Parkinson Action Network (PAN) is also excited to present their annual online Tulip Tribute Garden, where you can celebrate, honor, and remember your family and loved ones who have been touched by Parkinson's disease. You can [plant a virtual tulip](#) on their website at www.parkinsonsaction.org. Check it out!!

**Presbyterian Home for Central New
York's Parkinson Project**

The goal of the Project is to reconstruct the current 40 bed Parkinson residence into a "high tech" 34-bed environment that will enable each individual resident to live as independently as possible. Our primary goal, through advanced technology in voice and motion sensor equipment, is to develop and modify a living environment that is specific to each resident's needs and increase the resident's quality of life. The project will consist of two phases of construction. With the help of local architects Nelson Associates and contractor Beebe Construction, phase one will include such improvements as sprinkler system, heating/air conditioning and nurse's call system. Also an addition to the building will be constructed that will accommodate four residents. Phase two of the Project will be a continuation of constructing new resident rooms, an exercise room, and dining room specifically for Parkinson residents. We are proud and eager to see our concepts become a reality and hope that you will visit our campus soon to see the new and exciting services we have to offer.

Matt Cravis
Director of Community Relations & Marketing



Happy Easter!!!

POETRY CORNER

For Helen

Helen Sperling, gracious lady,
Proud I am to call her friend.
Helen Sperling, what a treasure!
The good she does will never end.
Victim of the horrors of the Holocaust.
So many of her people lost.
Dedicated to keeping truth alive,
Bravest woman I have ever met.
She has given us her best,
And we are truly blessed
To have so fine a woman in our midst.
Her spirit will burn brightly
Long after she is gone.
Helen Sperling, giving hope
And a reason to go on.

MFM

Enjoy and Share Pleasures

By Sharon Lee Kelley

Put a twinkle in your walk
besides a twinkle in your eye
So no matter what the challenge –
It's better to laugh than cry.
Enjoy the warmth from friends like the sun
Cheer on and support others – join in the fun.
We have only one life to live
Share humorous stories and lovingly give
Encouragement and kindness with a smile or grin
Let positiveness flourish and you are bound to win.
When people are complimentary
And of their time freely give
They help create a heaven on earth
And encourage others to better live.

EDITOR'S NOTE:

In looking for an appropriate article about caregivers, I found this article in the Winter issue of the Parkinson Post of the Parkinson Support Group of Upstate New York located in Rochester. With Carol's permission, I would like to share it with our readers. - Nancy

Carol's Corner by Carol Look, PSGUNY Past President

What are the criteria for being a perfect care partner?

The perfect care partner is:

“C” = Creative, Communicative, Compassionate

“A” = Active, an Advocate, Accepting of PD diagnosis

“R” = Relaxed, Rejuvenated, Rested

“E” = Energized, Encouraging, able to Enjoy the good moments

“G” = Gentle, Giving, Guilt-free

“I” = Imaginative, Invested, a cheerleader for independence

“V” = full of Vitality, Vigilant for danger signs like falls, choking

“E” = ready to Educate others about PD, Ensures physical and mental well-being

“R” = Reads to increase knowledge of PD

“S” = Spiritually strong, conscious of need to reduce Stress, Supportive of other caregivers

Put them all together and you have a good start to being a perfect care partner.

You are forgiven if you lose your cool sometimes, especially when cognitive problems like short term memory loss, difficulty comprehending everyday activities and possibly aggressive behavior alter the personality of the person with PD. When you feel your temper rising, remember my directive: “Take five deep breaths, then smile, or sing. Don't argue with your loved one – redirect the activity.

When good moments occur, enjoy your partner. When things are rough, forget them as soon as they're over. You will survive and you'll become one of the “perfect” care partners. Relax. I know a great many care partners and can honestly say I don't know of any who are imperfect. - Carol Look





In Memoriam

Helen E. Morgan Kinne of Utica passed away January 11, 2011 at Harding Nursing Home. She was the caregiver for her husband, Marvin J. Kinne, as he dealt with Parkinson's disease. Together they were members of CNYPSG, Inc. and were active participants in group programs. Helen was always an active member of her church and community. We extend our sympathy to her family and friends.

Edward A. McCaffrey of Rome died on February 28, 2011 after living with Parkinson's disease for more than twenty years. An active member of CNYPSG, Inc., he had served on the Board of Directors and as an officer. Ed enjoyed writing poetry and being a part of the M & M show to educate the public about PD. Our sympathy goes out to his family and friends.

We also extend our thoughts and prayers to Evelyn Petrie and her family for the loss of her brother, James A. Zipf, on March 5, 2011.

MEMORIALS

In Memory of Edward McCaffrey

by Nancy McCaffrey
Christine L. Bart
Sharon L. Kelley
Mr. & Mrs. Paul Worlock
Mr. & Mrs. Neal Casey
Catherine McEnroe
Herbert Freeman
Mr. & Mrs. Henry Tierney
Lucille E. Sheppard
Julie C. Sainz

by Mr. & Mrs. Dominick Spinelli
Mr. & Mrs. John Matterese
Mr. & Mrs. Donald Raymond
Mr. & Mrs. Alfred Remington
Mr. & Mrs. William Wolf
Mr. & Mrs. Stuart Greene
Mr. & Mrs. John Schmidt
Mr. & Mrs. John A. Barry, Jr.
Rome DC Chapter NYSARC Inc
Rome City School Nurses

by Baden P. Mudge, Jr.
Ann Lenio
Donald McCaffrey
Lillian M. Town
Jean Garlinghouse
Margaret Palmer
Evelyn Petrie
Mrs. Anna M. Gally
Kathryn Schaff

In Memory of William J. Zeiter, Jr.

by Geraldine A. Zeiter
William C. Zeiter
Antoinette Hyer
Catherine Colosimo
Marilyn M. Tyo
Anthony Militello
Diane Carville
Paula Fontaine
Robert D. Tuttle

In Memory of James A. Zipf

by Evelyn Z. Petrie
Mr. & Mrs. Patrick Moylan
Mr. & Mrs. John Schmidt

Donations to CNYPSG

Mr. & Mrs. Raymond A. Potasiewicz

Eleanor M. Angell

HMS Host

NURSING HOME ADDRESSES

Marjorie Renodin

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Margaret Bluff

Marion Burg

James Dexter

George Fanelli

Joe Giannantelli

Barbara Grogan

Victor Jarzombek

Sam Kitchen

Robert Luberda

Joan Manzelmann

Nate Thomas

Presbyterian Home for CNY
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New Hartford, NY 13413

Mae Mosher

VanAllen Nursing Home
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Little Falls, NY 13365

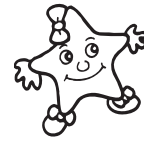
Margaret Hoskyns

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

Betty Langdon

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

Nancy's Nonsense



The Middle-Aged Teapot Song:

I'm a middle-aged man, short and stout.
Here is my beer gut, here is my pouch.
When I get all steamed up, hear me shout:
"Where's my remote? It was on the couch!"

Teacher/ Student questions;

TEACHER: Donald, what is the chemical formula for water?

DONALD: H I J K L M N O.

TEACHER: What are you talking about?

DONALD: Yesterday you said it's H to O.
(This kid is a future Rocket Scientist!)

TEACHER: Glenn, how do you spell 'crocodile'?

GLENN: K-R-O-K-O-D-I-A-L K-R-O-K-O-D-I-A-L

TEACHER: No, that's wrong . .

GLENN: Maybe it is wrong, but you asked me how I spell it!
(I Love this child)

TEACHER: Millie, give me a sentence starting with 'I.'

MILLIE: I is..

TEACHER: No, Millie... Always say, 'I am.'

MILLIE: All right... 'I am the ninth letter of the alphabet.'
(This one is going to be a Journalist!)

TEACHER: Harold, what do you call a person who keeps on talking when people are no longer interested?

HAROLD: A teacher . .



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

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

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Current resident or

CHECK YOUR MEETING DATES!!

APRIL 19TH



MAY 19TH



JUNE 21TH

