



NO PARKIN'

CENTRAL NEW YORK PARKINSON'S SUPPORT GROUP, Inc.

Vol. 18 No. 2 April 2009

Meeting Schedule – 3rd Tuesday – 12:30 PM

Presbyterian Home of CNY

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Calendar of Events

April 21, 2009

**CNYPSG, Inc. Annual Meeting
Election of new Board Members**

May 19, 2009

**Guest speaker – Sandy Smith
Director of Information Services
Presbyterian Home for CNY
Topic – High Tech Devices to aid
those with disabilities**

June 16, 2009

**Guest Speaker – Jane Devecis
Activities Director
Presbyterian Home for CNY
Topic – Activities for Parkinson's
Physical and Creative**



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: Barbara Grogan, Ann Lenio, John & Thea Matterese,
Pat Moylan, Myrtleann Seifried, Hank & Rose Marie Taylor

We are Family

I can almost guarantee that if you come to a meeting of the CNYPSG, you will leave feeling good about something. It might be the fine program that was presented or the excellent speaker. It might be the jokes told or the yummy goodies served during the meeting. Or it could be the great suggestions you picked up from talking to other PD patients about ways they handle that certain problem that's been bugging you. Possibly it's the new neurologist that you heard about whom several members were so pleased with. You've been looking for a fresh perspective on your disease. Or it might simply come down to the caring attitude of the people who were there.

It feels like family. You come away knowing these people really do care about one another and truly want to help each other out. You get the distinct feeling that they have come to the meeting, not to see what they can get for themselves, but to see what they can give to someone else.

It is a wonderful feeling, and it's been there right from the beginning. From the start of the group in 1992, before we even had a name, there was a sense of family involved. These people meet to share and to encourage one another. They share their fears and their successes, their expertise and their conflicts. Frequently they can answer each other's questions and help solve each other's problems.

Probably one of the best things is finding others who understand exactly what you are going through. For the PWP's it is such a joy to talk to another person who knows what it feels like to have PD, and for the caregivers it must be a great relief to have others to talk with about the special difficulties of caring for a Parkinson patient.

At a CNYPSG meeting you will see smiling faces, hear laughter, and witness a group of people enjoying each other's company and having a good time. If you or someone close to you has PD, give us a try.

MFM

*Honoring One of
our Best*

May 2, 2009 has been chosen as "Charlie Mahaffy Day" at a ceremony to be held at the Boonville-Oneida County Fairgrounds. The celebration will be held from 1:00PM to 5:00PM at the Kiwanis Building at the fairgrounds.

Charlie will be honored by the Boonville American Legion and other civil and religious organizations for his many contributions to the Boonville and area community.

He has served as Chaplain of the Boonville American Legion since 1956. Charlie has been a vigorous advocate for veterans for many years, and he still continues to promote veterans' services and organizations.

Mahaffy retired from the U. S. Postal Service in 1987 where he served as postmaster in Boonville.

His family has always been very important to Charlie and he was a vigilant caregiver for his wife, Norma, during her long illness.

Our Congratulations go out to Charlie! We are blessed to have him as a member of our support group!!



CNYPSG

Website

Check

it out!!

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

To our members and readers;

If anyone sees any articles in publications or on the internet that they feel would be of interest to our readers, please share them with us. We would be glad to use them in our newsletter. We are also open to new ideas for the newsletter.

HELP!!!

Marge and Nancy

Running for Research

At our March meeting we welcomed a new couple, Tami and Scott Koster from Bridgeport, NY. The Kosters came as visitors but left as new members of CNYPSG. They came to our group to ask for help in raising money for the Michael J. Fox Foundation's PD Research Program. Tami's family and friends are uniting to take part in the annual Utica Boilermaker and make it a fundraising event for Team Fox, which is part of the Michael J. Fox Foundation. Team Fox allows ordinary individuals to turn athletic events such as marathons, bowl-a-thons and tournaments into fundraisers for Parkinson disease.

Tami, a young onset PWP, was diagnosed five years ago and has been battling PD ever since. This fundraising project has been spearheaded by Tami's niece Amanda who first approached the Fox Foundation and, getting approval there, went to the Boilermaker authorities who also gave her the go ahead. Thus "Team Meed" has been created to represent Parkinson disease in this year's Boilermaker. The name comes from the fact that Tami's many nieces and nephews call her Aunt Mimi or Meed. Team Meed has recruited over 45 participants to either run or walk in one of the Boilermaker events, a 5K and a 15K run on Sunday, July 12, and a 3-mile walk on Saturday, July 11. Team Meed has representation in all 3 race categories. What they need now is sponsors. This is where we come in. Becoming a sponsor for Tami's team is an easy way for us to participate in this important research while at the same time bringing more Parkinson awareness to our area with a PD team at the Boilermaker. As you know the race attracts a huge crowd of both runners and spectators to our area. Media coverage reaches a vast audience.

If you would like to join the team or make a donation to this worthy cause and help Team Meed reach their fundraising goal of \$5,000, contact Tami by mail, phone

or e-mail. A contribution of any size will be appreciated. They add up! You will be sent an official contribution form and a preprinted envelope. Donations go directly to the Fox Foundation.

Tami Koster
8155 Knees Kern Rd.
Bridgeport, NY 13030
315-633-8002
E-mail: Auntmimi@twcny.rr.com



MUSIC
MUSIC

Celebrated grammy award winning pianist Joe Utterback will be performing to benefit the Parkinson Renovation project at the Presbyterian Home. The concert will take place at the First Presbyterian Church on Genesee St. in Utica on May 2nd at 7:00pm.

Joe performs annually at the Tony Awards Gala in New York City and in the lobby of the Empire State Building during the holiday season. Joe also performs solo concerts throughout the country.

We are honored to have such a wonderful pianist performing to benefit the Presbyterian Home.

The concert is May 2nd, 7pm, the tickets are \$15.00 per person and can be purchased in advance from the Community Relations Department of Presbyterian Home or with a credit card by calling 315-272-2273. Visit www.presbyterianhome.com for more information.

Come join us for a delightful evening and support the Parkinson's community!



Delusions

Delusions are defined as fixed thoughts or ideas that are often illogical, irrational and dysfunctional. The individual will wholeheartedly believe these thoughts or ideas even though they are not based on reality. There are many types of delusions. The most common types reported in PD are described below.

Type of Delusion

Jealousy Belief(s)

The belief that your partner is unfaithful.

Behaviors

Jealousy, false accusations, paranoia, aggression, social withdrawal.

Persecutory Belief(s)

The belief that you are being attacked, harassed, cheated and/or conspired against.

Behaviors

Paranoia, suspiciousness, agitation, aggression, defiance, social withdrawal.

Somatic Belief(s)

The belief that your body functions in an abnormal manner or an unusual obsession with your body and/or health.

Behaviors

Anxiety, agitation, reports of abnormal or unusual symptoms, extreme concern regarding symptoms, frequent visits with the clinician.

What You Should Know About Delusions:

- Delusions are less common in PD compared to visual hallucinations. They affect approximately 8% of patients. However, delusions tend to be more complicated and present a greater risk for behavioral disturbances and safety concerns.
- Delusions generally represent a more obvious deterioration or decline in one's condition.
- Delusions are typically more difficult to treat than visual hallucinations.
- Delusions are not only associated with medication side effects but dementia as well. As a result, delusional patients are often confused and extremely difficult to manage. In these cases, many caregivers require outside assistance from family members, neighbors, and/or home healthcare agencies.
- Delusions can begin as generalized confusion at night. Over time, this confusion can develop into clear delusions and behavioral disturbances during the day.
- All forms of delusions can be seen with PD although delusions of jealousy and persecution are most widely reported.
- Delusions of persecution (i.e.: paranoia) typically represent a greater challenge for treatment and general care by family members and loved ones. Patients are often suspicious, argumentative, defiant, and sometimes aggressive. This can pose a serious safety risk not only to the patient, but family members and caregivers as well. Paranoia can also lead to medication noncompliance, in which the patient refuses to take his/her pills because they are "poisoned" or "deadly".

Key Point: Delusions cannot be controlled by the patient. Delusional thoughts are not deliberate or consciously created. Therefore, patients cannot simply stop or turn off these thoughts. It is important to understand that these beliefs and ideas are as real to the patient as "the sky is blue". That is why delusions are often called "fixed", meaning they are set, rigid and inflexible

The Group Scoop

MEETING NOTES



Our first meeting of 2009 was held on January 20th and our guest speaker was Rebecca Maggio from the Lutheran Home. She spoke on their active day senior's program and the services they offer. Her presentation was well received and time was provided for sharing ideas. It is always reassuring to know the emphasis being placed on high quality care in the area. We thank Rebecca for joining us for the afternoon.

Pat Duciaume, Speech Therapist at the Presbyterian Home for CNY, was our February guest speaker of the day. Pat shared her expertise regarding the problems that people with PD and movement disorders deal with such as speech, volume, swallowing, choking, etc. We thank Pat for answering our questions and spending her valuable time with us.

In March we met on St. Patrick's Day and the green was evidenced by the different attire worn by our members. There was a good turnout for this meeting as we welcomed new people as well as those we hadn't seen in a while. We always look forward to meetings where we can initiate discussions among caregivers and Parkinsonians. Everyone seemed interested in the concerns expressed. It is always helpful and educational to give voice to those concerns and to follow up whenever necessary.

WELCOME!!

It is so exciting to have new people join us at our monthly meetings. It is great to have the opportunity to share information with them and get to interact with them. We are pleased to say "WELCOME" to Allen Gilberti, Esther Kitchen, Jean and Lanny Dixon, Betty Burns and Scott and Tami Koster. We look forward to having you all participate in our many activities.



Under the Weather?

Spring has sprung and we are hoping that our members and friends having health problems are on the mend! We send our best wishes to Barbara Grogan, Charlie Mahaffy, Myrtleann Seifried and Lillian Town.

CNYPSG, Inc. Annual Meeting

The annual meeting of the Corporation of the Central New York Parkinson's Support Group, Inc. will be held on April 21, 2009. The names to be voted on will be submitted by the Nominating Committee at this time. Three people need to be chosen by the Corporation to serve three year terms on the Board of Directors. The Board of Directors will meet later this month to select the officers for the coming year.

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

Hope

Of all of the forces that make a better world,
None is so powerful as hope.
With hope, one can think, one can work, one
can dream.

If you have hope, you have everything.

Anonymous

TEN THINGS EVERY PWP AND CARE PARTNER SHOULD KNOW

Adapted from Understanding Parkinson's Disease: A Self-Help Guide by David L. Cram, M.D., AddicusBooks.com

Ten Things Every PWP Should Know:

1. Remember the importance of a positive attitude.
2. Establish a good relationship with your doctor.
3. Learn as much as you can about your PD (so you can be in control).
4. Exercise daily.
5. Take your medications on time exactly as prescribed.
6. Don't let PD consume you: you are the master.
7. Contribute some service to your community (maybe to CNYPSG). It will nourish you emotionally and get your focus off yourself.
8. Attend a support group.
9. Remain as independent as you can for as long as you can but know when to ask for and how to graciously accept help.
10. Live each day to the fullest and never lose hope.

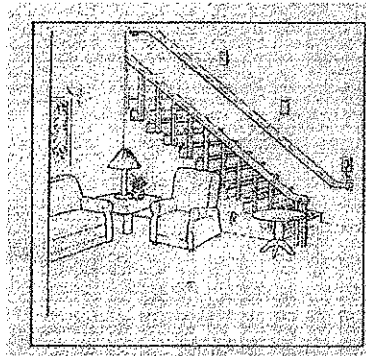
Ten Things Every Care Partner Should Know:

1. Understand the importance of taking care of yourself, too.
2. Remember it is normal to experience a wide range of feelings including those of anger, sadness, loneliness, guilt and resentment.
3. Develop constructive ways to channel emotions, for example exercise, talk with friends, keep a journal or practice relaxation techniques.
4. Practice positive self-talk.
5. Recognize signs of depression and seek help.
6. Arrange to make time for yourself – your own interests and friends.
7. Attend a support group.
8. Learn how to help your partner face physical and emotional challenges.
9. Let (and encourage) your partner to do as much as possible while they are still able.
10. Deepen your faith and spirituality.

David Cram, M.D. was a 54-year-old physician with a thriving medical practice in 1989; at the peak of his career when he was diagnosed with PD. After an initial nose-dive into depression and self-pity, Dr. Cram revived and in 1999 published a book based on his personal experiences.

WHAT IS A PARKINSON'S FRIENDLY ENVIRONMENT?

At a recent Support Group meeting someone referred to an article they had read asked, "What is a Parkinson's Friendly Environment?" Here's one answer. See if you can find at least six things that make this home easier for a PWP to manage. Answers on page 9.



A New Kind of Stem Cell

According to a Texas newspaper and on-line reports, Scott & White health system, in conjunction with the Texas A&M Health Science Center College of Medicine, recently recruited scientists to conduct pioneering research using stem cells gleaned from adults' bone marrow. Clinical trials involving diabetes patients are scheduled to begin in September, and other trials - including Parkinson's disease - are expected to follow.

Using local anesthesia, doctors extract less than an ounce of marrow from a hip bone. The stem cells in that material multiply, and when there are enough of the cells, they are injected into a patient's blood stream. It is theorized that they will attach to damaged tissues and either repair them or at least stop further damage.

Some of the trials will use stem cells gleaned from one person's marrow and injected in another person. Others will treat people with cells from their own bone marrow.

IN RESEARCH

A majority of Parkinson's patients had insufficient levels of vitamin D in a new study from Emory University.

The fraction of Parkinson's patients with vitamin D insufficiency—55 percent—was significantly more than patients with Alzheimer's (41 percent) or healthy elderly people (36 percent).

The finding adds to evidence that low vitamin D is associated with Parkinson's, said one of the study's investigators, Marian Evatt, M.D.

Evatt and her team compared Parkinson's patients to Alzheimer's patients because they wanted to evaluate the possibility that neurodegenerative diseases in general lead to vitamin D insufficiency.

Most Americans get the majority of their vitamin D from exposure to sunlight or by dietary supplements; fortified foods such as milk, and packaged cereals are a minor source. Only a few foods in nature, such as salmon and tuna, contain substantial amounts of vitamin D.

The body's ability to produce vitamin D using UV-B radiation from the sun decreases with age, making older individuals at increased risk of vitamin D deficiency.

"We found that vitamin D insufficiency may have a unique association with Parkinson's, which is intriguing and warrants further investigation," Evatt said. The connection could come partly because some people with Parkinson's have mobility problems and are seldom exposed to the sun, or because low vitamin D levels are somehow related to Parkinson's onset or progression.

Evatt said the study results are striking because the research subjects came from the Southeast, where, given the short winters, vitamin D insufficiency is not thought to be a factor.

In addition, the study found that insufficient vitamin D linked to Parkinson's the fraction of patients with the lowest levels of vitamin D, described as vitamin D deficiency, was higher (23 percent) in the Parkinson's group than in the Alzheimer's group (16 percent) or the healthy group (10 percent).

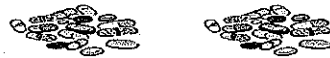
The study examined 100 people in each group, who were recruited between 1992 and 2007. Every fifth Parkinson's

patient from Emory's clinical neurology database was selected, and healthy controls and patients with Alzheimer's disease were matched on age and state of residence.

Doctors have known for decades that vitamin D plays a role in bone formation, Evatt said. More recently, scientists have been uncovering its effects elsewhere, including producing peptides that fight microbes in the skin, regulating blood pressure and insulin levels, and maintaining the nervous system. Low vitamin D levels also appear to increase the risk of several cancers and autoimmune diseases such as multiple sclerosis and diabetes.

Previous studies have shown that the part of the brain affected most by Parkinson's, the substantia nigra, has high levels of the vitamin D receptor, which suggests vitamin D may be important for normal functioning of these cells, Evatt said.

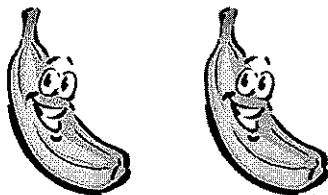
Source: ScienceDaily



GO BANANAS FOR A HEALTHIER COLON AND POSSIBLY FEND OFF PARKINSON'S DISEASE

Debbie Curran advises us to check out the Real Age web page for fascinating information that enables people to, as they advertise, "Live Life to the Youngest."

This month the focus is on bananas. Real Age asks, "What do bananas have in common with corn, eggs, salmon and spinach? All contain B6 which can cut your risk of colon and rectal cancer...a lot." Studies are also suggesting that "foods with this might also help stave off Parkinson's disease and depression." It's worth a try.



In Memoriam

Sarah Schachtler of Waterville passed away on February 6, 2009 at the Presbyterian Home for CNY after a long illness. Sarah and her husband, Peter, were charter members of CNYPSG, Inc. and were always active in our group activities until failing health prevented them from participation. Sarah also served on the group's Board of Directors. We will always remember Sarah for her sunny disposition and bright outlook on life. We send our sympathy to her family and friends.

Marie Bascom of New Hartford died on March 18, 2009. Marie had attended our group meetings some time ago. Our sympathy goes out to her family.

Marvin J. Kinne, a Utica resident, passed away March 28, 2009 at Faxton-St. Luke's Healthcare. Marvin was an active church member, a Boy Scout leader and owned his own shoe business at one time. Marvin, along with his wife, Helen, were participating members of CNYPSG until health problems persisted. We extend our condolences to his family and friends.

MEMORIALS

In Memory of Sarah Schachtler

by Mr. & Mrs. Patrick Moylan
Evelyn Petrie & family
Mr. & Mrs. John Schmidt
Mr. & Mrs. Edward McCaffrey
Mr. & Mrs. Bruno Piretti
Baden P. Mudge, Jr.

In Memory of Marie Bascom

by Mark W. Sweeney
Susan Pugliese
Ed Keeler
Rowene Bessey
Carol Rubel
Gorton Lake Assoc., Inc.
Diane Cone Kall

In Memory of Clifford T. Fletcher

by Mr. & Mrs. Charles Bach
Mr. & Mrs. Kevin Hayes
Ann & Terry Stedman
Ellen M. Dziekowicz
Pauline Rizzo
Peter & Roxanne Stolarczyk
William & Geri Owens
Fred & Laura Gerow

In Memory of Marvin J. Kinne

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

Donations to CNYPSG

Ron & Beth St. Marie

Mr. & Mrs. Norman Burak
Nancy DeMartino

Mr. & Mrs. Elliott Cummins

CNYPSG wishes to thank everyone for their generous contributions

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Helen Davis
Masonic Home
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Betty Langdon
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Utica, NY 13501

John DeMartino
Robert McVoy
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New Hartford, NY 13413

Nancy's Nonsense



Quasimodo goes to a doctor for his annual checkup.

"I think something is wrong with your back," the doctor says.

"What makes you say that?" Quasimodo asks.

"I don't know," the doctor replies. "It's just a hunch."

On a recent trip to Washington, D.C., my brother-in-law overheard a patriotic father pointing out a well-known building to his son. "You see that triangular -shaped octagon over there? That's the Pentagon."

Everyone knows I'm a stickler for good spelling. So when an associate e-mailed technical documents asking me to "decifer" them, I had to set him straight.

I wrote, "Decipher is spelled with a ph, not an f. In case you've forgotten, spell checker comes free with your software."

A minute later, I got this reply, "Mine must be dephective."

During rehearsal, the high school Music Director was beside himself. The cymbal player in the band was constantly coming at the wrong time with his cymbal clash. The young man maintained that his entry point gave a much better effect and that he wouldn't play it as written.

When the Music Director was asked by the Principal why he kicked the young man out of the band, he replied, "It was a simple case of cymbal disobedience."

ANSWERS TO QUIZ PAGE 6

1. Adequate lighting on stairs
2. Clear delineation of steps
3. Hand rail both sides
4. No throw rugs
5. No coffee table
6. No clutter
7. Electrical cords out of the way