



# NO PARKIN'

## **CENTRAL NEW YORK PARKINSON'S SUPPORT GROUP, Inc.**

**Vol. 17 No. 2 April 2008**

**Meeting Schedule – 3<sup>rd</sup> Tuesday – 12:30 PM**

**Presbyterian Home of CNY**

**4290 Middle Settlement Rd., New Hartford, NY**

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### **Board of Directors**

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## **Calendar of Events**

**Tuesday, April 15, 2008**

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

**Tuesday, May 20, 2008**

**Guest Speaker- Ann Tabrizi  
Subject - Humor**

**Tuesday, June 17, 2008**

**Guest speaker – Jo Petro  
Clinical Research Program Manager  
at Slocum Dickson**

**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.**

## *o 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

### **April is Parkinson Awareness Month**

By Marge Moylan

But you probably already knew that. If you are reading this newsletter, you most likely have more than a passing acquaintance with "PD," as I like to call him. He is an irascible old codger with a mean streak a mile wide. He gets his kicks out of causing pain and humiliation to PWP's (people with Parkinson disease) and to their caregivers, families, and friends as well.

Whether you are a novice or an "old pro" at playing this Parky game, you are VERY AWARE of PD's effect on your life. To the newly diagnosed he may be a far off specter in a dark corner, waiting to take you by surprise. To the old pros he is a way of life, who has changed all the rules of the game we are attempting to play. But newcomer or veteran, we are definitely AWARE of his looming presence

He is a big bully too. He delights in tripping us up so he can watch us fall and break bones. He robs us of our memory so that we can't find what we're looking for. We don't even remember what's lost. It gives him great pleasure to watch as we struggle to communicate with others after he has diminished our hearing and softened our speaking voices to a whisper.

Yes, I would say that most of you reading this are AWARE of that old devil PD. Unfortunately the general public is not aware of the devastation that PD can cause. I once had a Congressional Rep tell me that Parkinson's was that disease where you take a pill and everything is fine. People need to be told!

What can you do to help raise public awareness? A LOT!!

- Go out. Be seen.
- Join a support group.
- Participate in Parkinson activities to raise funds for research.
- Write letters supporting PD research.
  - Letters to the editor
  - Letters to your legislators

- Be prepared with facts
  - 1 out of every 100 people over the age of 60 will get PD
  - Of the newly diagnosed, 40% are under the age of 60. (PD is NOT limited to any age group.)
  - There is no known cause for PD and no cure. There is a lot of promising research being done, but it needs funding.

Yes, April is Parkinson Awareness month. If I had a nickel for every time I have written or spoken those words... Heck, why not think BIG. If I had a million dollars for every time I have written or spoken those words, I'd donate it all to Parkinson research and see how far we could get! I think I got it right. More later, after my next dose kicks in.

Margie

### **Traveling**

April has always seemed to be our time to travel. Pat and I usually found ourselves on the go during our spring break, which more often than not, came in April. Some years we went to Myrtle Beach, South Carolina, others to Florida. One year we went to Houston, Texas to spend Easter with my cousin Suzanne. But all that travel was in our pre-Parky years, before I was diagnosed with PD. That was in 1986, the year I had to take a disability retirement.

But disability didn't mean the end of our travels, just a different type of travel. We no longer hopped in the car with beach gear, a cooler and a map from AAA. Our preparations now include more planning, always a request for handicap assistance, which is usually given quite cheerfully, and use of handicap facilities in hotels.

We have traveled far and wide since I retired 22 years ago, mostly for Parkinson purposes. In 1994 our travels took us to our nation's capitol where we attended the first Parkinson Action Network (PAN) Forum along with CNYPSG member Mary Petrie Wrege. In 1997 the McCaffreys and

along with members of the Upstate Parkinson Support Group from Rochester to take part in the Parkinson Unity Walk in Central Park,

We have flown to Miami to watch as Nancy McCaffrey received a national caregiver's award from the NPF (National Parkinson Foundation). Pat and I have flown to Loma Linda, California and Atlanta, Georgia, to check out a surgical procedure for my PD, which I decided against both times.

In 2006 we took the train again and went to Washington, DC for the first ever World Parkinson Congress which included everyone: researchers, physicians, patients and caregivers from all over the world. My doctor recently told me that the next Congress will be held in Glasgow, Scotland. I've got to get to that one. My mother was born not too far from Glasgow. I have always dreamed of going there!

## Save the Date

The 6<sup>th</sup> annual Parkinson's Awareness Walk is Saturday September 6, 2008 on the grounds of the Presbyterian Home campus. We are excited to have Gretta Mitchell, widow of Donald J. Mitchell, former Congressman from the Herkimer area, as this year's grand marshal and honoree. Mr. Mitchell represented New York's 31<sup>st</sup> congressional district from 1973-1983. Mark your calendars and join us for a great time, as we raise awareness for Parkinson's disease. For more information contact the Presbyterian Home at 315-272-2273.

Laureen M. Howard

## POETRY CORNER

Limerick Lines

Has PD invaded your Life?  
Do you feel like a fork with no knife?  
CNYPSG,  
Where the meetings are free,  
May help you and your husband or wife.

Margaret F. Moylan  
Parkinson's Shuffle

I'd like to muffle  
The sound of my  
Parkinson's shuffle.

My left foot slaps down,  
Plunk, plunk, plunk,  
My right foot drags along,  
Clunk, clunk, clunk.

My body leans forward  
Inviting me to run.  
Walking downhill  
Is not much fun!

Balance is a problem:  
I try not to fall,  
For this would make  
The loudest noise of all!

Imelda Attridge

## WILL I?

Parkinson's attacked me again today.  
I wish to hell it would go away.  
But since it won't, I'll do my best  
To tolerate this awful pest.

Will I freeze entering the hall?  
Will I stumble? Will I fall?  
Can my cane help balance me?  
Or will my walker set me free?

Will tomorrow imitate today?  
Will my problem go away?  
Each day it seems there's something new.  
Heaven help me see it through!

Ed McCaffrey  
CNYPSG Website  
Check it out!!



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

*Editor's note: Occasionally we are asked about Parkinson's plus diseases or Parkinson's syndromes, devastating diseases similar in some aspects to Parkinson's disease. In fact, a few of our members in CNYPSG, Inc have identified themselves as having some of these. We think you will learn a lot from the following article.*

*nom*

### **ATYPICAL PARKINSONISM**

By Lawrence I. Golbe, MD Professor of Neurology, UMDNJ-Robert Wood Johnson Medical School, New Brunswick, NJ.

You may have been told by your doctor that you have not Parkinson's disease but "atypical Parkinsonism," "Parkinson's plus" or "Parkinson's syndrome." Confused?

What is "Parkinson's syndrome"?

A "syndrome" is a group of signs and symptoms that often occur together and may be caused by any of a variety of diseases. A "disease" is an abnormal process, usually with a specific cause. For example, the syndrome called the "flu," which includes fever, muscle aches, cough and headache, can be the result of any of several diseases, only one of which is an infection by the influenza virus.

Similarly a combination of slowness, muscle rigidity, tremor and impaired balance is a syndrome called "Parkinson's syndrome" or just "parkinsonism." The disease that most commonly causes it is "Parkinson's disease" (PD). PD is strictly defined as parkinsonism associated with gradual loss of certain groups of brain cells that, as they sicken, form within them microscopic balls called Lewy bodies.

Parkinsonism may also be caused by about a dozen diseases other than PD. Most of these cause other signs and symptoms in addition to the parkinsonism, which is why they are also called the "Parkinson-plus" disorders or the "atypical parkinsonisms."

#### **Progressive Supranuclear Palsy**

The most common atypical parkinsonism is "progressive supranuclear palsy" or PSP. There are only about 20,000 people with PSP in the US, while there may be one million with PD. What's atypical about PSP is its failure to respond to levodopa/carbidopa or other PD medications, difficulties looking up and down, an erect or even backwardly arched

neck posture, and the relative early appearance of falls, slurred speech and swallowing difficulty. Most of these features can occur in PD, but not with the intensity or frequency with which they appear in PSP. Instead of Lewy bodies, the brain cells in PSP have "neurofibrillary tangles." While Lewy bodies are mostly made of a protein called alpha-synuclein, neurofibrillary tangles are made of a different protein called "tau."

#### **Multiple System Atrophy**

The next most common atypical parkinsonism is "multiple system atrophy" or MSA. In addition to parkinsonism, MSA usually features the type of poor coordination and balance that arises from disorders of the cerebellum, giving some sufferers a "drunken" appearance. Other "atypical" features in most people with MSA are low blood pressure, sensations of being too hot or cold, constipation, urinary difficulties and brief episodes of shortness of breath or sleep apnea. These arise from "dysautonomia" which is a loss of brain cells that control the autonomic nervous system. The dysautonomia of MSA was called "Shy-Drager syndrome" before it was recognized in the early 1900's as part of a specific disease that can have several forms.

Like PSP, MSA causes earlier balance problems than PD and medication for PD usually has little benefit. However, there is medication for most of the dysautonomic features. In MSA, the protein that aggregates is alpha-synuclein, as in PD, but it does so in a different set of brain cells and looks different from Lewy bodies. The protein aggregates in MSA are called "glial cytoplasmic inclusions."

#### **Corticobasal degeneration**

The third leading atypical parkinsonism is "corticobasal degeneration"(CBD).

CBD affects one side of the body first and worst. This is also true, but to a far lesser extent, for PD. For PSP and MSA, the problem is usually symmetric, with left and right sides affected nearly equally. CBD, in addition to parkinsonism, features abnormal posturing of limbs called dystonia, abnormally heightened reflexes as elicited by tapping with a hammer, and small sudden, rapid involuntary movements called myoclonus. It's most distinctive feature is apraxia, which is the loss of the ability to

perform complex movements with the hands or feet. There is also difficulty with the ability to perceive the spatial features of objects. At present, no medication is effective, unfortunately, and the disorder is treated with physical therapy. In CBD, the protein that aggregates is tau, as in PSP, but it does so mostly on one side of the brain, and disproportionately in the area of the brain responsible for planning complex movement tasks, the frontal lobes.

#### **Dementia with Lewy Bodies**

"Dementia with Lewy Bodies" is a parkinsonian disorder that often starts with confusion, depression or psychosis (that is, hallucinations or delusions). However, the mental symptoms appear before or together with the movement symptoms and not afterwards, as in PD. The movement difficulty may even be very mild and as for most of the atypical parkinsonisms, tremor at rest is far less common than in PD. In DLB, the behavioral symptoms can vary greatly over periods of minutes to days and can include periods of unresponsiveness, elaborate delusions and visual hallucinations in addition to the difficulties with memory and thinking. The hallucinations of DLB can occur without levodopa or other dopamine – enhancing medications, while in PD, any hallucinations are a side effect of those medications. The parkinsonism of DLB responds to levodopa/carbidopa. The movement and behavioral symptoms can be severely and dangerously exacerbated by drugs that block dopamine such as Haldol (haloperidol). Compazine (prochlorperazine) and Reglan (metoclopramide).

#### **Vascular Parkinsonism**

Another common condition causing atypical parkinsonism is "vascular parkinsonism" or "arteriosclerotic parkinsonism." This is the eventual result of many tiny strokes. No one of which may be large enough to cause symptoms at the time it occurs. The strokes can be seen on an MRI scan. Over the years, the cumulative effect causes movement difficulty, especially with walking and other movement of the legs. The condition does not respond to PD medications, but its progression can often be slowed or even stopped by controlling risk factors such as high blood pressure, smoking, or high lipids. Physical therapy is helpful in dealing with the gait problem.

#### **How Do I Tell If I Have Atypical Parkinsonism?**

Atypical parkinsonism rather than PD should be suspected when someone with the parkinsonism syndrome has little or no response to a moderate dosage of levodopa/carbidopa or when there is the early appearance of falls, behavioral changes, swallowing problems, abnormal eye movements, bladder problems or lightheadedness on standing. The physician should order an MRI scan, which can show the small strokes of vascular parkinsonism, the asymmetric shrinking of corticobasal degeneration, the unusual pattern of brain shrinkage of progressive supranuclear palsy, or the abnormal pattern of iron and scarring of PSP or multiple system atrophy. Some other radiologic tests such as PET and SPECT can also be helpful in special circumstances.

While the atypical parkinsonisms are more difficult to treat than PD, the good news is that they do not run in families nearly as often as PD does. While 20-25% of people with PD have some close relative with PD, fewer than 1% of those with PSP, MSA or CBD have a relative with atypical parkinsonism. For DLB and vascular parkinsonism, the fraction is slightly higher. The causes of the atypical parkinsonisms are starting to be worked out. As we learn more about the abnormal processes in the brain cells in these conditions, treatments that may slow or even reverse their course will become possible.

Source: The APDA, Inc. Newsletter, Winter 2008 issue



#### **Black tea may lower risk of PD**

According to a study involving 63,000 Chinese men and women aged 45 to 74, regularly drinking black tea could help prevent the onset of Parkinson's disease (PD). Those who consume 23 cups of the beverage a month (less than eight ounces per day) are 71 per cent less likely to contract PD. Green tea had no observable effect on one's susceptibility to the disease.

Source: The PFHC Bulletin/February 2008

### Uncomfortable Drooling in Parkinson's Disease

Let's tackle a frustrating issue openly. It feels embarrassing when you cannot control the spit that builds up in your mouth. More than 70 percent of people with Parkinson's disease eventually experience some degree of drooling. Medical science has explored some strategies that might help people get around the difficulty.

In the December issue of *Movement Disorders*, four neurologists wrote an article about current treatments that are meant to relieve drooling – or sialorrhea in medical lingo.

Continuing with the theme of openness—the average person's salivary glands secrete more than a liter of saliva each day. Usually swallowing reflexes take care of it. However, people living with Parkinson's often lose that reflex. Parkinson's may impair the ability to swallow as well, only getting the job partially accomplished. As a result many people with Parkinson's end up with frustrating episodes of drooling.

There are some treatments that your doctor may consider for addressing drooling including:

- Anticholinergic medications
- Botulinum toxin injections
- Adrenergic receptor agonist medications
- Mouth surgery to reduce saliva production

Interestingly, one of the less scientific solutions is quite simple. "Chewing gum or sucking on hard candy may provide temporary improvement by serving as a motor or tactile cue to swallow more frequently, but this does not work for all patients," the authors write.

Doctors and researchers are also experimenting with reminder programs and other behavioral techniques to get people with Parkinson's to swallow more often. The research is still maturing.

If drooling is a problem for you, talk with your doctor about some of these strategies. Under his or her direction you may find strategies to stop the hassle.

Source: "Movement Disorders," December 2007

### Managing dizziness can help reduce fall risk

Dizziness affects balance safety and contributes to falling. Some people use the term "dizziness" to describe feeling unsteady on their feet, while others report feeling as if the whole room is spinning around them. Words like "lightheadedness," "wooziness," or "vertigo" also may be used to describe dizziness.

Many things may contribute to dizziness, including the following.

- **Low blood pressure.** Parkinson's disease and medications frequently given to treat Parkinson's can lower standing blood pressure. We recommend that people with Parkinson's routinely have their blood pressure monitored in both sitting and standing positions.
- **Multiple medications.** Taking four or more medications significantly increases the risk of side effects, including dizziness. Make sure your doctor is aware of all medications you are taking, and ask questions about potential side effects when taking a new prescription.
- **Not enough fluids.** Dehydration can result in dizziness and balance loss. Make sure you are drinking enough fluids, particularly during hot, humid weather or if you have been experiencing nausea, vomiting or diarrhea.
- **Stress and anxiety.** Stress may cause physical symptoms, including dizziness. Use relaxation techniques such as deep breathing, soft music or guided imagery if you are feeling stressed.
- **Alcohol.** Alcoholic beverages affect equilibrium and balance. Limit alcohol intake to reduce risk of dizziness and falls.
- **Other medical conditions.** Inner ear disturbances, cardiac problems, diabetes and depression are just a few of many other medical conditions that may cause dizziness.

Dizziness may be treated with medications, safety strategies, rehab therapies and good nutrition. Report feelings of dizziness to your doctor, who can recommend the best treatment options for your situation.

Source: "Satellite," Fall 2007, Struthers Parkinson's Center, Minneapolis, MN

*Happy Spring!!!*

# The Group Scoop

## **MEETING NOTES**



Our first meeting of 2008 was held January 15<sup>th</sup> when we were pleased to have Pierre Michaud, Marketing Representative for Continuing Care Services @ Faxton-St. Lukes. He described a number of services in the community which can be helpful to those people who need assistance with day-to-day health maintenance and support activities in order to remain in the comforts of their home. Some of the services mentioned were Senior Network Health, Mohawk Valley Home Care, Visiting Nurse Association, Lifeline and Meals on Wheels. We thank Pierre for providing us with this information.

Maureen Roe, Physical Therapist @ the Presbyterian Home of CNY was our speaker on February 19<sup>th</sup>. She stressed the need for all of us to get exercise and showed us some exercises that can be done to help keep us fit whether we are sitting or standing. We can exercise either in the privacy of our homes or in an established therapy program. Our thanks to Maureen for sharing her expertise.

Our appreciation goes out to Kathleen Paciello, Program Coordinator for Child Lead Prevention, who gave a very informative presentation about preventing lead poisoning at our March meeting.. She explained the incidence of lead poisoning, where the problems can be found and what must be done to prevent poisoning from occurring.

## **WELCOME!!**

WOW!! How nice it is to have lots of new people join us at our monthly meetings. In January Don Johnson, Howard Mason, Margaret Peer and Sid Shiffman were the first to join us in 2008. In February, Clay Boyce, Sharon Kelley, Jeannine Lewis, George and Sharon Romleski and Lois and Tim West were with us for our meeting, On March 18<sup>th</sup>, Thomas Nolan and Nate Thomas were with us for the first time as well as Maya Richardson who is doing an internship in Nursing Home Administration with Tony Joseph. A special **WELCOME** to

you all! We hope we can be of help to you and that you all will continue to join in our activities.



## **Under the Weather?**

Health issues continue to plague many of the members of CNYPSG, Inc. We sincerely hope that spring will bring healthier times to Emily Lewis, Charlie Mahaffy, Jo Schmidt and all of our members and friends.

## **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 15, 2008. Four people need to be chosen by the Corporation to serve three year terms on the Board of Directors along with one person to complete the term vacated by another member. The names submitted by the Nominating Committee to be voted on at this meeting are Norman Burak, Lois Greene, Ann Lenio and Myrtleann Seifried for the three year terms. Patrick Moylan's name was submitted to serve the remainder of the two year term. 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



*In Memoriam*

**Nicholas D. Laino** of Utica passed away on March 3, 2008 after a lengthy battle with Parkinson's disease. Nick and his wife, Nancy, participated in CNYPSG, Inc. activities for several years. We extend our sincere sympathy to his family and friends.

**Donna Testa** of Rochester passed away on March 3, 2008. Donna was a member of the PD Support Group in Rochester. Donna and her husband, John, have been long time friends of CNYPSG, Inc. Our thoughts and prayers go out to her family and friends.

We also extend our sympathies to CNYPSG, Inc. members, Umberto and Gina Giannandrea on the death of their son, **Frank Giannandrea** on March 17, 2008.

**MEMORIALS**

**In Memory of Nicholas D. Laino**

by Mr. & Mrs. Patrick Moylan  
Mr. & Mrs. Edward McCaffrey  
Sharon Gregory – HCCC  
Vincent Casale  
Jackie Woudenberg  
Rebecca Ruffing

**In Memory of Frank Giannandrea**

by Mr. & Mrs. Patrick Moylan

**In Memory of Donna Testa**

by Mr. & Mrs. Patrick Moylan

**In Memory of Robert Lorenz**

by Karl Schmidt

**In Memory of Florence Helfand**

by Mr. & Mrs. Elliot M. Helfand

**In Memory of Dave Parmon**

by Jean Sterling

**Donations to CNYPSG**

Betty A. Wollaber

Eleanor M. Angell

Thomas W. Nolan

New Owl's Grill

**CNYPSG wishes to thank everyone for their generous contributions.**





## NURSING HOME ADDRESSES

**Margaret Bailey**  
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**Helen Davis**  
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**James Dexter**  
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**John DeMartino**  
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New Hartford, NY 13413

## Nancy's Nonsense



A tour guide was showing a tourist around Washington, D. C.

The guide pointed out the place where George Washington supposedly threw a dollar across the Potomac River.

"Big deal," said the tourist. "A dollar went a lot farther in those days."

\*\*\*\*\*

I took a part time job as an opinion poll sampler. On my very first call, I introduced myself, "Hello, this is a telephone poll."

The man replied, "Yeeeah, and this is a street lamp!"

\*\*\*\*\*

A window salesman phoned a customer. "Hello, Mr. Brown," said the Sales Rep, "I'm calling because our company replaced all the windows in your house with our triple-glazed weather-tight windows over a year ago, and you still haven't sent us a single payment."

The customer replied, "But you said they'd pay for THEMSELVES in 12 months!"

\*\*\*\*\*

The chef at a family-run restaurant had broken her leg and came into our insurance office to file a disability claim. As I scanned the claim form, I did a double take. Under "Reason unable to work," she wrote: "Can't stand to cook."



# KEEP SMILING!!!