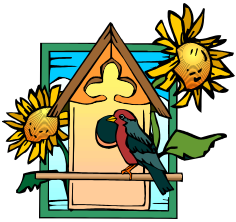


**Summer  
2007 Edition**



# The Parkinson's Bulletin

June-August  
Summer 2007



ROBERT WOOD JOHNSON  
UNIVERSITY HOSPITAL

## Atypical Parkinsonism

**Dr. Lawrence Golbe, UMDNJ-RWJMS**  
**Professor of Neurology, UMDNJ-Robert Wood**  
**Johnson Medical School**

### INSIDE THIS ISSUE:

Some people reading this may have been told by their doctor that they had not Parkinson's disease but "atypical parkinsonism" or "Parkinson's syndrome." Confused?

A "syndrome" is a group of signs and symptoms that often occur together and may be caused by any of a variety of abnormal processes in the body. On the other hand, a "disease" is a specific abnormal process happening inside the body, usually with a specific cause and usually with a variety of outward signs and symptoms. For example, the *syndrome* of fever, headache and rash can be caused by such *diseases* as chickenpox, measles or Lyme disease.

The combination of slowness, muscle rigidity, tremor and impaired balance is a syndrome called "Parkinson's syndrome" or just "parkinsonism." The most common disease causing this as part of its outward manifestations is "Parkinson's disease." PD is strictly defined as a gradual loss of certain areas of brain cells that, as they sicken, form microscopic balls called Lewy bodies that are mostly a protein called alpha-synuclein.

Parkinsonism is caused by about a dozen diseases other than PD. All 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."

The most common atypical parkinsonism is

is "progressive supranuclear palsy" or PSP. There are only about 20,000 people with PSP in the US, while there are about 500,000 with PD. What's "atypical" about PSP is its failure to respond to levodopa/carbidopa or other PD medications, the presence of difficulties looking up and down, an erect or even backwardly arched neck posture, and the relatively 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. The brain cells in PSP have not Lewy bodies, but "neurofibrillary tangles," which are made of a different protein called "tau."

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" feature 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 loss of brain cells that control the autonomic nervous system, or "dysautonomia." The dysautonomia of MSA was called "Shy-Drager syndrome"

**Continued on page 8**

Atypical Parkinsonism	1
Coordinator's Corner	2
President's Notes	3
Annual Parkinson Conference	4
Excellence in Service Award Recipients	6
Meet the Artists Show	8
Reflections on World Parkinson's Congress	10
	12
	12



## Coordinator Corner-Elizabeth Schaaf

Dear Friends,  
We certainly had a busy Spring!

On March 31st, we had well over 200 people attend our Annual People with Parkinson's and Family Conference at the Pines Manor in Edison, NJ. Topics included

During the conference, we also presented our third annual Excellence in Service Awards. Please see pages 4 and 5 for photographs.

I hope you enjoy the photographs from all our Spring events (Annual Conference, Parkinson's Unity Walk in Central Park, Meet the Artists, ) throughout the newsletter. Photos in this newsletter were taken by Anne Dalin, John Wherry, Peter Buckley and Kathleen Johnson.

Upcoming Falls events are : *Ask the Neurologist About Parkinson's*, *Newly Diagnosed seminar*, *Living Well With Parkinson's Telephone Series*, *Painting With Parkinson's* and *Parkinson's Disease Management Conference (November 10)*. More details in September Newsletter.

I hope you have a happy and safe summer. I hope to see you soon in the Fall!

Sincerely,

Elizabeth Schaaf

## March 31, 2007 Conference-Special Thanks To:

### Staff

Kathleen Johnson  
RWJUH, Community Education  
Department

### Volunteers

Sheila Aronberg, Anne Marie Konopka Anne Dalin (Photographer), Ben Yip, Shirley Hom, Karen Powers, Dick Powers, Nikki Taussig, Barbara Tanz, Dick Powers, Karen Powers, Claire Salamon, Marilyn Schaefer, Anna Buckley, Peter Buckley, Cathy Lear, Bill Lear, Margit Pinter, Lisa

*Claire Salamon secured the many, many fabulous door prizes for our conference. Thank you, Claire!*

### Conference Sponsors

Teva Neuroscience, NJ Chapter American Parkinson Disease Association, Medtronic, and Schwarz Pharma, Vernalis,

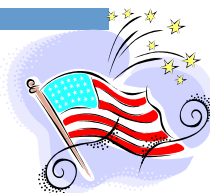
### Conference Exhibitors

Parkinson's Unity Walk, American Ramp, Healthcare Depot, NJ Chapter APDA, Medtronic, and Schwarz Pharma, Awaken to Africa, RWJUH Home Healthcare, Vernalis and Teva Neuroscence.

### Gift Certificates and Prizes

Movado Group  
Clarion Restaurant-Edison  
Red Lobster East Brunswick  
The Barge Restaurant Perth Amboy  
Wegman's  
"Comfort of Home" by Susan Imke  
Olive Garden East Brunswick  
Lafontana-New Brunswick  
International House of Pancakes East Brunswick  
American Red Cross First Aid Kit  
ShopRite Store  
Cranbury Station-Cranbury, NJ  
Applebee's  
Soho-New Brunswick  
Catherine Lombardi's-New Brunswick  
Frog and the Peach-New Brunswick  
Borders-Princeton, NJ  
Cheesecake Factory-Edison, NJ

## President's Notes-Bill Lear, NJ APDA Chapter President



**Bill Lear, NJ  
APDA President**

Spring has sprung. The budding of flowers and trees are all signs of new beginnings.

The Ridgewood Symphony Orchestra donated \$3,200 to the NJAPDA at a benefit concert on March 2, 2007, attended by Nikki Taussig, our friend Janet Sorkin and Cathy and I.

Many thanks to Pete Buckley, Cathy and Mitch Pitra, and Ben Yip and their families who worked to provide information about Parkinson's Disease to a cast of thousands who visited the booth at the New Jersey Home Show Expo at Raritan Center. Over \$250 was collected in our water bottle. Our annual symposium was a rousing success due in large to the efforts of Elizabeth Schaaf and Kathleen Johnson, to whom we are most grateful. There were many members who worked "behind the scenes" to create an appearance of ease and insure that everything runs smoothly. Without all of you this conference would not have been possible. The Walk-A-Thon was a huge success. We added one more bus and two more stops to the route for the walk. Everyone had a great time. With our continued fund raising efforts researchers can continue to advance toward finding a cure.

**Cathy and I invite you to join us at our "lake house" on Saturday, July 1, 2007, from 1PM until ????????** Join us for a day of fellowship and sharing many good things to eat. Please call **845.7333.7764** at the lake to RSVP.

As many of you know, Cathy and I are at a juncture of new beginnings. Cathy will retire in July and we will move to our "lake house" where we will remain until the fall. We will "winter" in Seattle with our daughter Wendy, her husband Mark and two of the best grand-daughters one could have, Sarah and Julia. We will return to Baltimore to be with our son Doug for a while, then back to the "lake house". That is the plan. Ha...ha...ha Cathy and I are looking forward to it.

Now the hard part. It is with great reluctance that I tell you that I am stepping down as President of New Jersey APDA at the end of my term August 31, 2007. It has been a wonderful journey making and meeting new acquaintances like Michael J Fox and Janet Reno but not forgetting the old and faithful ones. Winning the award as one of six outstanding presidents in the country in 2005 was one of the highlights as president. I will always cherish that moment.

I will never forget those who walked with me thru this sometimes rough journey who are no longer with us, like Marvin Wiess, Peg and Jack Mac-Millian. I would like to thank the APDA National Office Vince, Joel, Dr. Paul, Charlene and Michael the bearer of gifts and all the staff for there strong support and advice. I have worked with many I&R coordinators but the best come last. Elizabeth Schaaf has been the one person who has held it all together. She has gained national recognition as an I&R coordinator.

I will miss each and every one of you. TILL WE MEET AGAIN,

*Bill Lear*  
*NJ APDA Chapter President*

***Donation address for the NJ APDA has changed to:  
NJ APDA Chapter, PO Box 2026, Edison, NJ***

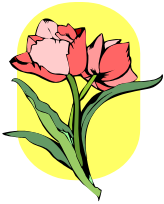
### ***A Study of Insomnia in Patients with PD***

We invite PD patients who are suffering from sleep problems to find out more about this research study.

You must be between the ages of 35-85 years old.

By volunteering to be a participant you will be providing valuable information to our understanding of effective treatments for this disorder.

**Please call us at:  
1-877-795-4673**



# Annual People With Parkinson's and Family Symposium March 31, 2007 The Pines Manor-Edison, New Jersey



*Dr. John Murphy speaking to the group on PD and medical management.*



*View of the conference exhibits.*



*Kathy Johnson, RWJUH Office Manager handling registration.*



*Susan Imke, Nurse Practitioner speaks to audience on the 10 Commandments of Coping with PD.*



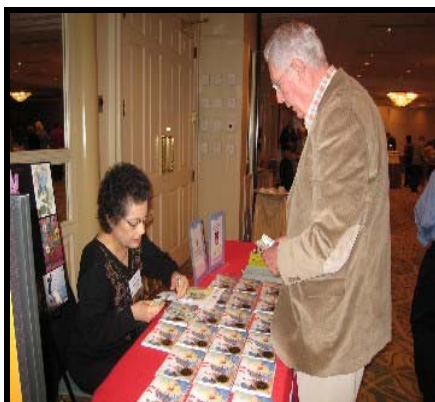
*Our Shelia Aronberg and Marilyn Schaefer (left) greet attendees at our March PD Conference.*



*Dr. David Heydrick, Neurologist and person with Parkinson's present the theories of his book, the Parkinson's Pyramid.*



*Amy Comstock, President and CEO, The Parkinson's Action Network speaks about Advocacy and PD.*



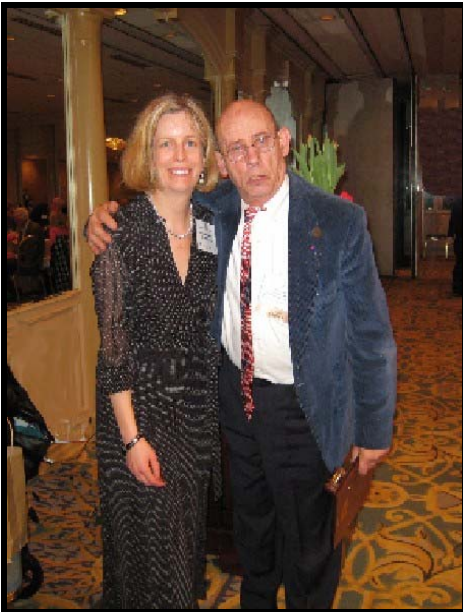
*Nikki Tausig, Treasurer, NJ APDA selling greeting cards featuring artists with Parkinson's. Proceeds go to the NJ APDA Chapter.*



*Carol Walton, Executive Director of The Parkinson's Alliances speaks about the Unity Walk.*



## *2007 Awards and Recognition Ceremony March 31, 2007*



*Elizabeth Schaaf with Bill Lear, President of the NJ APDA accepting a plaque for his many years of dedication and service as President of the NJ APDA Chapter.*



*Annie Konopka received the Excellence in Service for her dedication and hard work to raise awareness and funds for Parkinson's disease.*



*Donald Mason with his friend and fellow Moose Lodge board member accept an award for the NJ Moose Lodge Association for their generous support of the NJ Chapter APDA.*



## 3rd Annual Meet the Artist Gallery Show April 12, 2007

On Tuesday, April 12, the works of thirteen artists were featured at our second Annual Meet the Artist Gallery Show in the Arline and Henry Schwartzman Courtyard at Robert Wood Johnson University Hospital, New Brunswick, New Jersey.

The featured artists and their media are: Elena Tuero, painting; Joseph Dawley, painting, Chandra Guha, painting and Jeff Belpanno, and Anne Marie Konopka, paintings; Bill Evans, Margit Pinter, Virginia Smith and John Wherry, photography; Judy Peterman, needlepoint, Frances Yen, painting, and Shu Hau Lai.

Many of the artists pursued their media before being diagnosed with Parkinson's disease. Others discovered their artistic talents only after diagnosis, yet all continue to find time to create since the onset. All the artists agreed that art helps them to better cope with Parkinson's disease and lifts their spirits. Visitors to the Gallery Show praised the quality and diversity of the work, and showed their appreciation by selecting many of the items available for purchase.

If you are an artist and have Parkinson's disease, please contact the office so that we can update when we hold other art related events in the future. Please also check a very exciting website showcasing people with Parkinson's and their art. See other side of the page for details.



*Judy Peterman (PWP and artist) with husband Seymour Peterman*



*John Wherry poses with Doug from the Parkinson Disease Foundation and the PD Creativity Project.*

### PDCREATIVITY.ORG

*The PDCreativity.org Project is a beacon of light in the darkness that is Parkinson's disease. Our mission is to help improve the quality of life for people with Parkinson's (PWPs), by shedding light on the therapeutic value of creativity and encouraging them to pursue their own forms of artistic expression, whether it is music, dance and photography or jewelry making, and painting. Features of the website include the following:*



***The Gallery:*** the work of artists living with PD.

***The Artists:*** contact information and personal statements.

#### ***The Forum:***

- Research related to Quality of Life.
- Resources listing classes that augment creativity.
- Happenings listing upcoming events.
- Comments/Articles highlighting personal triumphs, dealing with adversity, and tips on making your life easier.

*Inspired by the first-ever World Parkinson Congress, held in February of 2006, PDCreativity.org is dedicated to helping improve the lives of people living with Parkinson's disease.*



***Please visit the PDCreativity website!***



*Anne Marie Konopka poses with one of her paintings.*



# Meet the Artist Gallery Show-April 12, 2007



*Elena with her pieces of art work; oil paintings; still-life and other subjects.*



*Ginny Smith and her husband Bill Smith her photographs.*



*Frances Yen poses with her artwork.*



*Gloria Dawley with her husband Joseph Dawley's work.*



*Chandra Guha (left) with caregiver, Anna Cruz.*



*Bill Evans with his photographs.*



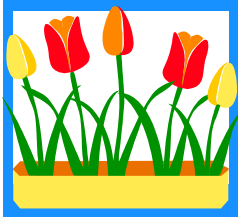
*Shu Hau Lai, a new artist with this year, with her paintings.*



*Jeff Belpano with his paintings and prints.*



*Margit Pinter with her friend near her artwork, jewelry and clothing display.*



## *Reflections on the Word Parkinson Conference-2006*

### **By Margit Pinter**

The first World Parkinson's Congress in Washington, D.C. was held February 23-26, 2006. The huge Convention Center was just the best place that could have been selected for the site of this event.

This was the first time I experienced being a participant in a large medical setting. This was a new milestone for both my husband and me, as he accompanied me there as a caregiver. I was first diagnosed with P. D. (Parkinson's Disease) on January 28, 2004. At that time all of my unasked questions were addressed by the "experts". On this day many answers to my unvoiced questions of the others were given with clarity and factual information. This was the day my whole life took on new meaning.

(It took a while to learn more about how this life threatening progressive disease would have an effect on me. I realized that I would have to take harmful medications that would change and create problems in my day to day routine activities, and how I would manage time with my family and friends.) At the opening ceremony, approximately three thousand (3,000) persons were gathered together in one place with many questions related to the same topic, "Parkinson's Disease (P. D.)

As a Reiki Master, and a Parkinsonian artist, I felt an enormous quantity of "energy flowing from the crowd through my body," there was only one thought in my mind. "WE ARE NOT ALONE." There were many medical doctors, physical therapists, nurses and researchers from hospitals and clinics, pharmaceutical representatives and P. D. persons, from all over the world, who had traveled from far and near to make these meaningful days for us. They share their experiences truthfully and gave a clear concept of the knowledge of what is known about the disease with us.

Listening to speakers and watching on the stage, as a dance that became descriptive in my mind and titled "Off and On." The dance was the best performance that I have ever witnessed. It was a true scene happening in the life of a daughter and her father. The father is afflicted with P. D. and the daughter senses all the movements and trembling of him as the disease is progressing. It was so emotional at this time, I burst in tears with the same thought, "we are not alone."

The exhibition of the Parkinsonian Artists was the best idea

for a program. It was exciting to see people interested in the eleven (11) categories that were displayed. Luckily, one of my three (3) pieces, a photo, "The Sunset Before the Storm," was among the chosen ones to be on exhibition. There were people who were not in the condition to walk around, but were accommodated with chairs that made enjoyable to see the artworks from moving slides that were on either side of the exhibition. The exhibition was open during the lecture hours, in addition to each afternoon and evening when movies, plays, poems and songs were performed. Daily from 6 P.M. Parkinsonian artists who were present explained their work. There were other activities for those who were interested in yoga - exercise equipment was available for everyone. Different shaped and sized drums were available for those of us, who were enjoying the rhythm of being able to demonstrate that "we are not alone." We were actually enjoying being away from home with interesting things to do, rather than focus on our medical ailments.

By the wrap up of the Congress, we all had made a lot of friends, and a lot richer with knowledge knowing that one day Parkinson would be defeated.

Working on an art piece helps me to keep my mind off my condition, think positively and moving my fingers to my goal.

In conclusion, "We have hope," after attending the First World Parkinson Congress in Washington, D. C.

Thank you so much for providing everyone of us with an opportunity of sharing an unforgettable experience.

**SAVE THE DATE!!!**

**Fall Parkinson's Conference in  
Southern NJ**

**Saturday, November 10, 2007**

**10:45 to 3:00**

**The Mansion**

**Voorhees, New Jersey**

*Look for more details and registration in the  
Fall Newsletter.*

## Continued from page 1

before it was recognized in the early 1990'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.

The third leading atypical parkinsonism is "corticobasal degeneration." 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 rapid involuntary movements called myoclonus. Its most distinctive feature is apraxia, which is a 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.

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 parkinsonian movement difficulty, especially with walking and other movement of the legs. The condition does not respond to PD medication, 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. ##

### *Parkinson Disease Clinical Trials*



Do you want to learn more about current trials for Parkinson's disease?

Go to [www.pdtrials.org](http://www.pdtrials.org)

## RESEARCH ON MEMORY, MEDICATION, AND PARKINSON'S DISEASE AT RUTGERS-NEWARK

Professor Mark A. Gluck, co-director of the *Memory Disorders Project* at the Aidekman Neuroscience Center at Rutgers University-Newark seeks patients with Parkinson's disease to participate in research studies designed to improve our understanding of the disease and its treatment. The studies can be conducted either at Rutgers-Newark or in people's homes in the greater NJ/NY region.

The project is part of an ongoing NIH-funded investigation of cognition, attention, and memory function in patients with Parkinson's Disease, with a particular focus on better understanding the role of dopaminergic medication and how this interacts with the disease. The long-term goal is to develop treatments for the disease which optimize both the patients motor skills and cognitive and memory function.

For these studies we are interested in recruiting individuals with mild-to-moderate Parkinson's disease. In addition to administering a comprehensive neuropsychological evaluation, participants will be asked to perform various computer "games" which are designed to evaluate specific cognitive and memory capabilities in Parkinson's patients.

Participants in our studies will be paid \$20/hr. For more information on these studies and how to participate, please contact our Research Coordinator, Lisa Haber-Chalom, either by phone at (973) 353-1080 x-3222 or via email at [lhchalom@andromeda.rutgers.edu](mailto:lhchalom@andromeda.rutgers.edu).

Additional information on the Gluck lab at Rutgers can be found at <http://www.gluck.edu>

**NJ APDA Chapter's Address has  
Changed!**

Please send any donations now to:

**NJ APDA Chapter  
PO Box 2026  
Edison NJ 08818**



## *13th Annual Parkinson's Unity Walk New York Central Park-April 28, 2007*

New York, April 28, 2007 - "The sea of people is amazing," exclaimed Michelle Charlesworth, ABC-TV news media anchorwoman and master of ceremonies as she addressed the attendees of the 13th Parkinson's Unity Walk, held under sunny skies on Saturday, April 28th, in New York City central Park.

The crowd has been growing since 1994, when Margot Zobel founded the Walk to raise awareness of Parkinson's disease and funds for Parkinson's research. "There were only 200 people walking that day- but we felt we were making history. We raised \$16,000, and, as we had pledged, every penny was turned over to research," stated Margot.

Since then, the Unity Walk has built upon the success of each previous year, increasing Parkinson's awareness, and much-needed funds for research, making it the largest annual event for Parkinson's disease. Saturday's crowd is estimated at over 11,000 people and we are sure that we will exceed last year's \$1.4 million. And, as pledged since the inception of the Walk, every penny raised continues to go directly to Parkinson's research. This is made possible through the Unity Walk's premier sponsor, Boehringer Ingelheim Pharmaceuticals, the national sponsor, The Weather Channel and others including, Medtronic, Inc., Novartis, Schwarz Pharma, Teva Neuroscience, Valeant Pharmaceuticals, and Vernalis.

Prior to beginning the Walk, the crowd gathered around "Find the Cure Boulevard." The participants took advantage of the Ask the Doctor Booth, PDtrials, presenting the latest information on clinical trials, and the major U.S. Parkinson's organizations and corporate sponsor's provided education on Parkinson's disease and drug therapies.

At noon, the vast crowd gathered in the stage area as Michelle Charlesworth introduced a panel of speakers. Martin Tuchman, Chairman of the Unity Walk, read from a proclamation from Mayor Michael Bloomberg declaring it Parkinson's Unity Walk Day. Margot Zobel, Founder of the Unity Walk, was greeted with a standing ovation. Maryum "May May" Ali, Muhammad Ali's daughter dazzled the audience with charm and her poem and Lonnie Ali, caregiver and wife of Muhammad Ali made a heartfelt speech and stated a sincere thank you to Michael J. Fox for what he has done in the community. Davis Phinney, Founder and President of the David Phinney Foundation, motivated the crowd with an uplifting speech. Amy Comstock Rick, Chief Executive Officer

of the Parkinson's Action Network and Anne Udall, Chairman, Parkinson's Action Network and daughter of Morris K. Udall, both greeted the crowd and gave enthusiastic speeches.

The Alan Bonander Humanitarian Award was presented to Tamra Cantore for her exceptional work in the Parkinson's community. Michelle Charlesworth then introduced actor Michael J. Fox. The crowd reacted with thunderous applause as he passionately spoke about Parkinson's and the importance of the Unity Walk.

After the prize drawings and announcement of the top teams and individual fundraisers, the checkered flags were raised to mark the start of the Walk beginning at approximately 1:00 p.m. at the bandshell in Central Park near 72nd Street. Thousands of people, including more than 300 teams, walked the relaxing, wheelchair-accessible, 2-mile circular path under blue skies, sunshine, and gentle breezes.

All funds raised from the Walk are designated for research and will be distributed among the major U.S. Parkinson's disease foundations, including the American Parkinson Disease Association, the National Parkinson Foundation, The Parkinson Alliance, Parkinson's Disease Foundation, The Parkinson's Institute, Michael J. Fox Foundation for Parkinson's Research, and Parkinson's Action Network. ##



**Sayreville residents, Rose McTiernan (left) and Claire Salamon (Right-Vice President of the NJ APDA) accept a Parkinson's proclamation from Mayor Kennedy O'Brien during an April Borough Council Meeting.**

# 13th Annual Parkinson's Unity Walk New York Central Park-April 28, 2007



*Peter Buckley with his friends and family; team name was Pete's Pals.*



*Claire Salamon and MameMame Ali Meet during the opening ceremony of the Unity Walk.*



*Grace Evans with Bill Evans, being a good sport with his hat. Promised friends he would where a hat that would make him stand out in the huge crowds.*



*Dr. Matthew Menza and Lori Ramig, Speech Pathologist at the Ask the Doctor table answering the questions about PD from people with Parkinson's, families and friends.*



*Northern NJ Support Group (Montclair Support Group) chat while waiting for the bus.*



*Jeff Belpano and Holly Belpano listening to the speakers prior to start of the walk.*



The days are finally getting warmer and with the sun setting late hopefully more folks are getting out for longer and longer walks. I've been asked several times if I think walking is a good idea for people with Parkinson's (PWP). My answer is emphatically YES.

Walking has long been considered one of the best exercises. It stretches the muscles, flexes the joints, expands the lungs and exercises the heart. What's more it's great for piece of mind.

But don't take my word for it.

A group in Sweden did the research to document the value of walks in the park. For one week in autumn, over a period of three consecutive years, this group took a total of 12 persons with Parkinson's Disease to a mountain retreat where they participated in daily walks of about 4 kilometers (a little over 2 miles) on the soft trails of the lower hills.\* These individuals ranged from 60-78 years of age and were found to be mildly to moderately affected by Parkinson's disease.

Testing comparing before and after the week demonstrated improved mobility not only immediately after the week in the mountains but even 3 full months later. The results indicated long-lasting improvement in decreased time to initiate movement, improved postural stability and improved balance. The participants also voiced and demonstrated improved self confidence after returning home.

Of course it remains up to each individual to determine what safe exercise is for them. For some it may be an evening stroll on the sidewalks of their neighborhood using their walker. For others it may be a robust hike on a woodland trail. But the point remains the same - the journey to wellness begins with a single step. So walk as often as you can.

Remember Sir Isaac Newton's first law: "A body at rest tends to stay at rest, a body in motion tends to stay in motion..." I like the second part and I bet that so do you.

## Take a Walk in the Mountains

David C. King, PT, MS  
Kessler Institute for Rehabilitation

\*Sunvisson, Lökk, Ericson, Winblad and Ekman, "Changes in motor performance in persons with Parkinson's Disease after exercise in a mountain area", Journal of Neuroscience Nursing 1997 Aug; 29(4):255-260.



### Parkinson's Support Group Meetings-RWJUH

**Wednesday, June 20, 2007**

Afternoon PD Support Group  
Location: RWJUH Auditorium,  
New Brunswick, NJ  
Time: 7:00 pm to 8:30 pm.

**Thursday, June 21, 2007**

Afternoon PD Support Group  
Location: RWJUH Auditorium,  
New Brunswick, NJ  
Time: 12:30 pm to 2:30 pm

Topic for both meetings: **Carbs or No Carbs?  
That is the question.**

Also questions and answer period with  
Marcus regarding other nutritional issues re-  
lated to Parkinson's disease.

**Speaker: Marcus Garand, RD-Outpatient  
Dietician**

**Robert Wood Johnson University Hospital**

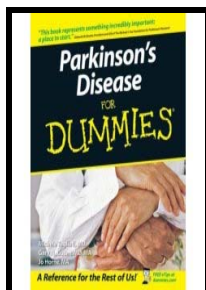
### **PLEASE NOTE!**

**No Meetings in July or August this year.**

**Our next meetings after June will be in Sep-  
tember (third Wednesday and third Thurs-  
day of the month)**

**Look for support group meeting details for  
the fall newsletter.**





## Parkinson's Disease For Dummies

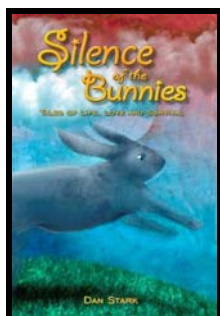
by Michele Tagliati (Author), Gary Guten (Author), Jo Horne (Author)  
\$13.99-paperback

The book covers the following topics:

- How to ensure an accurate diagnosis
- How to assembling and working with your health care team
- Informing others about your condition
- Choosing the most effective medications
- Establishing a diet and exercise regimen
- Considering surgical options, complementary medicine , and clinical trials
- Maintaining healthy personal and professional relationships
- Adjusting your routine as your PD progresses

### Silence of Bunnies: Tales of Life, Love and Laughter By Dan Stark

Order an autographed copy today! \$15.00 Available directly from the author — danstark@mac.com. Also available from: Amazon and Barnes & Noble



*"This book makes you laugh out loud at times, and cry at others. In the end, it offers hope. It is essential reading for those with Parkinson's disease, and those who love someone who has it."*-Margaret Tuchman, President and Founder,

Parkinson's Alliance.

### Tai Chi Parkinson's Exercises For Patients and Caregivers DVD-\$19.95



Available for purchase through parkinsonsexercises.com. Improve your balance flexibility and coordination through the art of Tai' Chi. Our video is for those with Parkinson's Disease and their caregivers. Created by Jerry Wild, an expert with over 32 years of experience and a Parkinson's patient.

## Depression and Social Support in Parkinson's Disease (PD)

**A study for PD patients and their families funded by the National Institutes of Health (NIH)**

### Do you have PD and suffer from these symptoms?

- ◆ Getting more and more isolated
- ◆ Feel sad or empty most of the day
- ◆ Difficulty falling asleep or staying asleep
- ◆ Loss of interest in daily activities
  - ◆ Unable to concentrate
  - ◆ Feeling tired all of the time

## HELP US FIND ANSWERS

Dr. Roseanne Dobkin at the Robert Wood Johnson Medical School in New Jersey is conducting a 10-week treatment study of depression in PD. **The study treatment does not involve medication** and helps people to change thinking patterns and behaviors that may be related to depression.

All research care including an extensive psychiatric evaluation is provided at no cost to those who qualify. A friend, family member, or significant other will also be asked to participate in the study. *Participants are paid \$20.00 for each study evaluation.*

**For more information, please call Dr. Dobkin at:  
732- 235-4051**

Books and tapes above are also available on loan with the NJ APDA Parkinson's I & R Center; call (732) 745-7520.



## *Music Therapy Benefit Individuals with Parkinson's Disease*

Concetta M. Tomaino, D.A., MT-BC

Executive Director/ Co-Founder, Institute for Music and Neurologic Function

Music Therapy has proven to be particularly effective for persons with Parkinson's Disease (PD). Research in both music therapy and in neuroscience have shown that music can affect function in very profound ways. In fact, some neuroscience studies have shown that certain types of music stimulate dopamine and serotonin – two neurotransmitters (chemicals produced by brain cells) that are diminished in PD patients - production in the brain.

Many individuals with Parkinson's have problems with initiation and consecutive movement. They also have problems with slowness of movement or bradykinesia. Music, particularly rhythm, can become a template for organizing a series of movements. This process is not automatic. The rhythm must stimulate the impulse or will to move in the PD patient in order for the impulse to transfer into real movement. The music therapist explores various rhythmic patterns or musical styles with the patient to establish which patterns will help with walking, balance, and movement in general. Patients report that by focusing on the rhythm and trying to feel its pulse they can better walk or perform consecutive tasks where previously they froze.

In addition to movement, patients with PD may have problems with articulation where their speech becomes slurred and unclear. Sometimes this is due to poor breath support and sometimes as a result of difficulties with the motor aspects of speech, ie moving the mouth and tongue to articulate a specific sound. Patients are encouraged to "sing" and sustain single syllables to promote greater breath support. They are also encouraged to tap their hand while they speak as this aids in the coordination and clarity of their speech.

Sometimes the patient with PD has too much movement and can't stop the tremors or involuntary movements referred to as dyskinesia. The urge to move may impede the need to relax and may even disrupt sleep. In these instances, slow rhythmic music can slow down over active body rhythms and induce relaxation and sleep. Other aspects of Parkinson's Disease can affect a patient's mood causing depression, anxiety and or even social isolation. Participating in music therapy groups, including therapeutic drumming groups, dance and movement groups, and music therapy support groups, can provide an outlet for self expression and a closer connection to others. Active music therapy can aid in promoting both physical as well as emotional health and well being.

Individuals with PD should explore the benefits of music therapy in their overall care. There are a few self help techniques that can be tried at home.

- Explore various styles of music, eg, latin, reggae, rock, marches, etc. and find those songs that make you want to move.
- Create a music library of "music to move by" and bring a portable CD along so that you can play this music while walking. Be careful when using headphones outdoors as this may distract you from paying attention to other sounds in the environment eg, motor vehicles, bicyclists, etc.



- Explore music that you like to sing to and use these recordings to help keep your voice strong.
- Create a "memory" library of your favorite music. Familiar music helps stimulate recall of old memories and meaningful moments in our lives.
- Explore music that makes you feel relaxed and use this music when you can't fall to sleep.
- Participate in group music programs such as a local chorus or social dancing.
- Find a music therapy program in your area..

**For more help or additional information please email [info@musichaspower.org](mailto:info@musichaspower.org).**



**For a listing of Parkinson's Support Groups in NJ, please call (732) 745-7520.**

Please note that a new group is forming soon in Edison, NJ. Please call Jackie at (732) for more information on this new support group and to be added to their mailing list. Look for further details in the Fall Newsletter as well.



**Book title:** *Parkinson... ¿y qué?*  
**Author:** Maria Elena Reyes  
**Language:** Spanish  
**Cost:** \$10

This is a unique book written in Spanish, where love and care brings hope to people living with

Parkinson's, family and caregivers.

Her author, Maria Elena Reyes was diagnosed with Parkinson's Disease, gathered strength and founded the "Asociacion Puertorriqueña de Parkinson" a National Parkinson's Foundation Chapter in Carilina, Puerto Rico.

Her desire is to share her experience and bring hope and support to those in need and to put up the fight against Parkinson's Disease.

If you would like to order this book you can write and send payments to:

**Maria Elena Reyes**  
**Asociacion Puertorriqueña de Parkinson**  
**P.O. Box 7079**  
**Carolina, PR 00986**  
**Fax: (787)752-0650**

Note: This book is written and available only in Spanish, for more information please. Write to above address.



## WEB CORNER

[http:// www.youngparkinsons.org](http://www.youngparkinsons.org)

Information for those who have Young Onset Parkinson's disease.

<http://www.caregiver.org>-Information for caregivers from the Family Caregiver Alliance.

<http://www.parkinsonaction.org>-Learn about advocacy information related to Parkinson's disease.

<http://www.wemove.org>-Comprehensive web resource for movement disorder information and the hub of movement disorder activities on the web. Information for patients, families and health professionals

## *Parkinson's Disease and Depression*

**A handful of additional patients are needed for this NIH funded study of depression in PD. It is important that the investigators are able to finish the study as soon as possible - we need to have answers to the question of how to treat depression in PD**

*A study of depression in patients with PD funded by the National Institutes of Health*

**Do you have PD and suffer from these symptoms?**

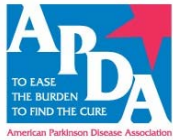
- ◆ *Getting more and more isolated*
- ◆ *Feel sad or empty most of the day*
- ◆ *Difficulty falling asleep*
- ◆ *Difficulty staying asleep*
- ◆ *Loss of interest in daily activities*
- ◆ *Unable to concentrate*

## **HELP US FIND ANSWERS**

Dr. Matthew Menza at the Robert Wood Johnson Medical School in New Jersey is conducting a study of depression in PD using medications approved for depression. All research care including an extensive psychiatric evaluation is provided at no cost to those who qualify. *Participants are paid \$30.00 for each study visit.*

If you or someone you care about is interested in participating, please call Allison Dicke, toll free at:

**1-877-795-4673**



**ROBERT WOOD JOHNSON**  
UNIVERSITY HOSPITAL

**NJ APDA Parkinson I & R Center**  
120 Albany Street, Suite 360  
New Brunswick, NJ 08901

Phone: 732-745-7520  
Fax: 732-745-3114  
Email: Elizabeth.schaaf@rwjuh.edu

**New Jersey American Parkinson Disease Association Information & Referral Center**

**Jacob Sage, MD**  
Professor of Neurology  
Chief, Movement Disorder Clinic  
UMDNJ/RWJMS

Medical Director, NJ/APDA  
Parkinson Disease Information & Referral Center

**Elizabeth Schaaf**  
Coordinator & Editor  
NJ/APDA Parkinson Disease  
Information and Referral Center,  
and  
Coordinator, Community Education  
Robert Wood Johnson University Hospital  
(732) 745-7520  
(732) 745-3114-fax  
Elizabeth.schaaf@rwjuh.edu

**Kathleen Johnson**  
Community Education Department  
(732) 418-8110

**Bill Lear, President**  
APDA New Jersey Chapter  
908-206-1018  
Hwl227@aol.com

**Donations to:**  
NJ APDA Chapter  
PO Box 2026  
Edison NJ 08818

**American Parkinson Disease Association**  
**National Office**  
135 Parkinson Avenue  
Staten Island, NY 10305  
Phone: 1-800-223-2732  
www.apdaparkinson.org



*Annie Konopka, Mrs. South Brunswick 2007 and contestant for the Mrs. NJ Pageant-May 5, 2007 in Atlantic City with her husband Joe, son, Jake and daughter Haley. Annie was also a recipient of the People's Choice Award and First Runner Up, Community Service. Congratulations Annie!*



**Moving? Or Have You Moved?**  
**Address/Name Correction Form**  
**PD Newsletter**

*NJ APDA Parkinson's Disease Information and Referral Center*  
*120 Albany Street, Suite 360*  
*New Brunswick, NJ 08901*

**Name (s)** \_\_\_\_\_

**New Address** \_\_\_\_\_

**Old Address** \_\_\_\_\_

**New Phone** \_\_\_\_\_

**Email** \_\_\_\_\_

**Comments** \_\_\_\_\_

