

The Parkinson's Bulletin

December 2008/February 2009



Winter 2008-2009



ROBERT WOOD JOHNSON UNIVERSITY HOSPITAL

The NJ/APDA Parkinson Disease
Information and Referral Center
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Parkinson's Disease: Mind, Mood and Behavior

Mathew Menza, MD, UMDNJ-RWMS
Professor, Psychiatry & Neurology
Interim Chair, Department of Psychiatry

The physical aspects of Parkinson's disease (PD), such as tremor, rigidity and postural imbalance, are the defining characteristics of the disease and they understandably receive the most attention from physicians and the press. Nonetheless, Parkinson's disease affects people's lives in a much broader sense than merely by physical impairment. For example, many of the non-motor aspects of PD, such as depression, insomnia and memory difficulties, are common and greatly affect your lives and those of your caregivers. These non-motor aspects of PD have not been well studied though, with the encouragement of advocacy groups, some studies have begun that help to guide clinicians and patients in how to treat these problems.

Depression, which occurs in roughly half of individuals with PD, is among the most common of the non-motor problems and causes substantial personal suffering. It is also associated with increased disability, greater cognitive decline and greater caregiver burden. Despite the adverse consequences of depression it appears to be under-recognized and under-treated. Depression can take many forms, but if you are feeling persistently sad, find yourself becoming socially isolated, don't have any interest in

things that used to bring you pleasure or are starting to think a lot more about things that used to bring you pleasure or are starting to think a lot more about death, talk to your doctor.

Sleeping difficulties are also common in individuals with PD and greatly affect quality of your life and daytime functioning. Many different sleep problems may be seen in individuals with PD, most of which require a diagnosis by someone with expertise in this area. Sleep problems can be thought of as difficulty with too little sleep (insomnia) or too much sleep (hypersomnia). Within the category of too little sleep, one might have difficulty falling asleep or difficulty staying asleep (or both). The most common problem in PD is difficulty staying asleep, referred to as sleep fragmentation. Insomnia may be related directly to PD or to the medications used for PD. Insomnia may also be related to other conditions, such as depression or other medical illness or to other primary sleep disorders, such as sleep apnea, restless legs or REM behavior disorder (RBD). Among the problems characterized by too much sleep are sleep attacks and excessive daytime sleepiness,

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Save the Date!
*Annual Spring
PD Conference*



*Saturday,
April 4, 2009*

*The Imperia
Somerset NJ
(New Location this Year)*

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*Hello From the Coordinator
Elizabeth Schaaf,
NJ APDA Parkinson Disease
Information & Referral*

Dear Friends:

I hope this newsletter finds you well and enjoying the holiday season.

Before this year comes to a close, I wanted to share with everyone a preview of upcoming events for 2009.

The Parkinson's Action Network's 15th Annual Research and Public Policy Forum will be held March 15-17, 2009 in Washington D.C. I have attended this event in prior years and have found it to be a very worthwhile and informative forum. You will have the opportunity to listen to leading scientists in the field of Parkinson's, and network and lobby on capitol hill regarding important healthcare issues for people with Parkinson's and their families. Scholarships are available but limited. Apply today. **Please refer to page 3 for details.**

On **Sunday, March 22, 2009**, the NJ American Parkinson Disease Chapter invites you to participate in our **Strike Out Parkinson's Bowl-a-thon Fundraiser** at Brunswick Zone-Carolier Lanes in North Brunswick. Please refer to page 13 for more details. Please register by March 12.

On **Saturday, April 4, 2009**, we will present our **Annual Spring Living Well with Parkinson's Conference at Imperia in Somerset, NJ**. Please save the date! Brochures with further details will be sent to you in February. We have a wonderful slate of speakers planned. Please join us for this event. Save the date and help us spread the word.

Look for more details about the Parkinson's Unity Walk and the bus(es) to the walk in the next newsletter. You may also contact the Unity Walk in later December for the official walk date (**1-866-789-9255 or go www.unitywalk.org**).

Wishing you a very happy and safe holiday season! I hope to see you soon in the new year.

Warm regards,

Elizabeth Schaaf

**NJ American Parkinson Disease
Association Information and Referral Center
Elizabeth.schaaf@rwjuh.edu**

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both of which may be related to PD or to the medications used to treat it.

Changes in a person's behavior may also accompany PD. This can range from relatively minor impulsivity to major changes like hallucinations and involvement in gambling. These changes can be extremely upsetting to patients and families but are generally treatable. While they may often be embarrassing and difficult to discuss with your physicians, they must be addressed. Most often, these problems are related to the medications used to treat the movement disorder and therefore require careful evaluation. A failure to evaluate and treat these problems can lead to even more difficult situations.

Memory difficulty, while generally mild for most people through most of the course of the illness, can develop and present great challenges. Again, careful evaluation by a physician who is familiar with PD is essential as it can help to determine the cause of the memory problem and also help to guide treatment. Many community resources are available for families if the memory problems become worse. Discuss these options with your physician and in the support groups.

Rather than try to give you guidance on how your doctor will evaluate and treat each of these problems (this kind of information is available in a variety of publications and on the web), I would like to give you some general tips on how to approach getting help. Also, I want to give you some general tips on what you can do to help minimize these problems and lead healthier life.

First Steps

There are a number of important points to consider prior to visiting your doctor, regardless of what problem you are having.

1. Be prepared when you go to your physician. Write down the problems you are having and come in with as much information as you can. For example, keep track of when the problem started, how often it is happening, etc. Make sure you have a list of your medications and when recent changes to those medications were made. Also, bring a list of your other doctors.

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President's Notes

Benton Yip

*NJ Chapter, American Parkinson
Disease Association (NJ APDA)*

Dear Readers:

With the election of President-Elect Barack Obama, it is anticipated that federal spending for medical research will increase, budgets for the NIH, CDC, and FDA will stop facing another year of cutbacks. The election of President-elect Obama will see many positive changes that were blocked by an ideological President strongly supported by the conservative wing of the Republican party. It was mentioned recently that Obama will issue an executive order reversing the prohibition of certain types of stem cells from being used and will lift the federal ban on funding for universities and corporations that pursue such research.

The funding for all research has seen nearly eight years of decline while funding for war has seen steady increases. Another bright outlook of the elections is the return of many Congressional Democrats especially Rep. Frank Pallone (D-6th district) who serves as Chairman of the Health Subcommittee within the Energy and Commerce Committee.

The important priority is to provide our scientists the means to pursue research to find a cure. This is our opportunity for New Jersey to develop a stem cells facility, get federal funding for Parkinson's research, financial incentives for doctors to become movement-disorder specialists, and funding for education and awareness programs.

We don't have to wait for January 20th, 2009 for Obama to be sworn in, we can take action now by writing to our representatives as well as to Rep. Frank Pallone to let them know what is important to us.

Regards,

Benton Yip

Benton Yip
President, NJ Chapter APDA
njapda@gmail.com

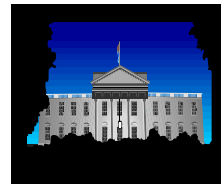


COMING SOON THIS
WINTER
PBS Frontline
Special on
Parkinson's

[http://www.pbs.org/wgbh/pages/
frontline/parkinsons/](http://www.pbs.org/wgbh/pages/frontline/parkinsons/)

Tuesday, February 3, 2009.

**Please check your local listings
for the time in your area.**



*Join Parkinson Action
for the 15th Annual
Scientific and Advocacy
Forum*

March 15-17, 2009

Washington, DC

*Scholarships are available online
but limited.*

You must apply by early January 2009

Phone-1-800-850-4726 or

202-842-4101

<http://www.parkinsonaction.org>

Don't miss this forum!

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2. Bring someone with you who is familiar with your problems. Another observer will often have a different perspective on your problem which will be helpful to your physician.
3. Remember that some things you experience are not related to PD. For instance, aging, pain, most medical illnesses as well as depression and anxiety are all associated with worsening sleep, so not all sleep difficulties that happen to individuals with PD are attributable to D.
4. Also, pay attention to what your lifestyle is like. For example, review stress, exercise, caffeine, etc. and have this information available when you see your doctor.

How to help yourself

1. There are many things you can do for yourself. Exercising, eating well, addressing stress in your life and attending to all of your health issues can all help improve the quality of your life and improve the control of your movements.
2. Stay involved with family and friends. It becomes increasingly difficult to force yourself to stay involved with family and friends – resist isolation.
3. Get involved in support groups. The many individuals in support groups represent a wealth of common experience – there are often many practical tips on how to handle common problems as well as emotional support from people who have faced similar problems. These groups can also be very valuable for family members
4. Get involved in advocacy groups. Serving a cause greater than yourself can improve your sense of well being and help to improve resources for the study of the illness. Without the advocacy groups, and many brave individuals who contribute to these groups, we would not have many of the advances that are so important to the treatment of PD.
5. Donate time and money to the search for better treatments.
6. Find things that you can still do and still enjoy. Everyone needs something to look forward to, some reason to get up in the morning.
7. Read about the illness. The more informed you are the better you will be to manage the problems you encounter.
8. Don't be afraid to tell your family and physician about problems you are having – seek out help.

Here are some internet resources and books:

Advocacy Groups

Parkinson's Disease Foundation (PDF) www.pdf.org
 American Parkinson's Disease Association (APDA) www.apdaparkinson.org
 Michael J Fox Foundation www.michaeljfox.org
 National Institute of Neurological Disorders (NINDS) www.ninds.nih.gov
 Parkinson's Action Network (PAN) www.parkinsonaction.org

Clinical Trials

www.clintrials.gov
www.PDtrials.org

Books

Psychiatric Issues in Parkinson's Disease: A Practical Guide. Eds. Menza, M., Marsh L. Taylor & Francis. 2006



So, Parkinson's disease presents many challenges for individuals and their families but you can do many things to improve how you meet these challenges.



Support Group Corner

A New Support Group is looking to form in Clifton, NJ (Passaic County). They are in need of a co-facilitator to help with meetings and other group responsibilities.

Please contact Elizabeth at (732) 745-7520 if interested.



Parkinson's Disease and Dystonia

Fiona Gupta, MD,

Hackensack University Hospital

The field of Movement Disorders involves neurological conditions that affect the speed, fluency, quality and ease of movement. Abnormal movements may encompass slowed or absent voluntary movement (bradykinesia) or excessive, involuntary movement (hyperkinesia). Parkinson's Disease (PD) and Dystonia are two conditions that Movement Disorder Specialists commonly treat. Dystonia is a syndrome characterized by sustained muscle contraction associated with abnormal movements and can be classified into primary or secondary dystonia. Parkinsonism is a clinical set of symptoms and signs consisting primarily of a combination of tremor, slowness of movement or bradykinesia, rigidity and disturbance of gait and balance. While these conditions are usually separate entities, Parkinsonism and dystonia may coexist in a number of neurodegenerative, genetic, toxic, structural and metabolic disorders. Dystonia is also a major clinical symptom that can occur in patients with Parkinson's Disease.

Dystonia is frequently encountered in young-onset patients with Parkinson's Disease. It may be the initial symptom of PD, with other features such as tremor, stiffness or slowness occurring shortly after. Parkinson's Disease has an asymmetric onset in most cases, therefore dystonia usually occurs on one side of the body first. Dystonia can be classified into focal, segmental or general. The focal dystonias are the most common and are limited to one area of the body. Dystonia in the setting of PD is often focal and include blepharospasm which involves the muscles around the eyes. Patients experience rapid blinking or even forced closure of the eyes. Apraxia of eyelid opening can also be associated with PD, in which patients have difficulty with opening the eyes. Cervical dystonia, also known as spasmodic torticollis, can also be associated with PD. This affects muscles of the neck, causing the head to rotate to one side, to pull down towards the chest or back, or a combination of these postures. Focal limb dystonia affects a single muscle or small group of muscles in the arms or leg and can be frequently encountered in PD.

The majority of cases of dystonia herald the onset of PD involve the feet. A term called equinovarus deformity involves dystonic posturing a foot with extension of

the big toe. This can also occur in the hand with abnormal joint flexion, sometimes called 'striatal hand'. These both may be seen in up to 10% of untreated patients with PD. They are usually reversible with medical or surgical therapy, but if left untreated may progress to a fixed deformity.

Thirty percent of patients with Parkinson's Disease experience dystonic, often painful movements of the lower limbs, such as painful toe-flexion. Primary dystonia on its own rarely starts in the lower extremities in adults. Therefore, the possibility of PD as a cause for a patient presenting with an isolated foot dystonia should be strongly considered.

Dystopia affecting the trunk and back can also occur in PD. Scoliosis and kyphoscoliosis, which is a spinal deformity combining sideways curvature and hunching forward of the upper part of the spine are frequently encountered. An extreme of this is marked flexion of the trunk called camptocormia. This postural abnormality is worse when standing and walking however patients may completely straighten their trunk when lying down or when leaning against a wall. Patients with camptocormia often feel a sensation of being pulled to the floor.

Levodopa (Sinemet) is the gold standard for symptomatic treatment of PD. It provides the greatest antiparkinsonian benefit with the fewest adverse effects in the short term. However, dystonic posturing can occur in patients with PD that are treated with levodopa. Dystonia can occur when the effects of levodopa start to wear off, it can also occur at the height of levodopa effectiveness. Dystonic movements and postures increase in frequency and severity with longer duration of levodopa treatment. Levodopa has a variable effect on dystonia in patients with PD, in that it may improve or exacerbate it. The dystonias seen in the "off" period, or when levodopa has not attained full effect are often painful and tend to occur either when the benefit of levodopa is wearing off or early after levodopa is taken. The term dyskinesia means abnormal, involuntary movements which appear as writhing movements of the face, trunk and extremities. This can occur with levodopa at its maximal effect. Dystonia may also be superimposed on these movements. This type of dystonia is often painless and can manifest as involuntary contractions of the mouth and jaw.

Aside from Parkinson's Disease, there are a myriad of conditions know as "Parkinson's Plus" Syndromes. These are a group of diseases featuring the classical features of Parkinson's Disease (tremor; rigidity; akinesia/bradykinesia;

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postural instability) with additional features that distinguish them from PD. These include Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA) and Cortico-Basal Ganglionic Degeneration (CBGD). PSP is a neurodegenerative disease that results in diffuse cell loss and atrophy. Slowness of movement, rigidity, eye movement abnormalities and postural instability with falls are prominent. PSP is associated with many types of focal dystonias including cervical and limb dystonia and blepharospasm, which often occur on one side of the body. MSA is a neurodegenerative disease associated with parkinsonism, loss of coordination and severe blood pressure fluctuations. Dystonic manifestations include cervical dystonia, particularly anterocollis, which is extreme anterior flexion of the neck. This can greatly limit swallowing function. CBGD is associated with parkinsonism, rigidity and the inability to execute voluntary movement or apraxia. Dystonia is a frequent feature in this condition, and can often be the initial manifestation. The dystonia in each of these conditions usually exhibits a sub-optimal response to levodopa.

Treatment for dystonia associated with Parkinson's Disease is highly variable. Levodopa has been used with mixed results. If a patient is experiencing "off"-period dystonia, certain dopaminergic agents that serve to potentiate the effects of levodopa may be helpful. Anticholinergic medications such as Artane, or muscle relaxants such as Baclofen or Clonazepam have been used with some success.

Botulinum toxin (BTX) injections have revolutionized treatment options for dystonia. BTX is a biological therapeutic agent that relaxes overactive muscles. Proper injection into affected muscles has proved quite successful and provides relief for 3-4 months. The effects are not permanent and injections have to be repeated every 3 months.

Deep brain stimulation (DBS) is an FDA-approved treatment for PD and also very successful in treating dystonic symptoms that are refractory to pharmacologic treatment. The DBS system consists of a lead that is implanted into a specific brain structure by a neurosurgeon. This lead is connected to a pacemaker-like device, or neurostimulator, that is implanted in the chest cavity. The lead and neurostimulator are connected by a wire that is tunneled down the neck under the skin. It is a programmable device that requires regular follow-up visits to adjust stimulation parameters in order to optimize symptomatic benefit while minimizing adverse effects. Dystonic symptoms that

occur in PD typically respond very well to deep brain stimulation.

In summary, while dystonia and Parkinson's Disease are two separate clinical conditions, they can overlap, and dystonia can often be the initial symptom of PD. A careful history and examination should be performed by your physician to determine what type of dystonic symptoms are occurring and whether there is a relation to PD treatment. At that point, therapy can be instituted whether it is with medication, botulinum toxin or deep brain stimulation.

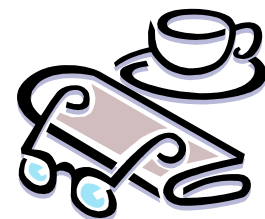
Dr. Fiona Gupta
Movement Disorder Specialist
680 Kinderkamack Rd. Suite 300
Oradell, NJ 07649
(201) 342-2550



**LENDING
 LIBRARY
 AVAILABLE!!!**

The Information and Referral Center has a lending library comprised of books, tapes and videos relating to Parkinson's disease.

Items are on loan for 21-day intervals and are mailed to your home.



***[http://www.patientslikeme.com/
parkinsons/community](http://www.patientslikeme.com/parkinsons/community)***

Online support for patients and families.



Music and Dance and Parkinson's Disease **David King, PT, MS** **Kessler Rehabilitation Institute**

Music and dance exist in almost every culture. Cultures that have never had contact with each other have the love of music and dance in common. Music has the power to evoke every mood and every state of mind there is.

I love music and I love to dance. As I work with my patients I often whistle or hum to give them cadence and they all enjoy it and most agree it helps them move. I've even used dance turns and spins with many of my patients that I know to have a history of dancing and they find them easier to perform than turning in place on their own accord.

What makes music and dance such powerful instruments for therapy in Parkinson's Disease? Oliver Sacks, MD the author of numerous best selling books including *Awakenings* was interviewed for the January 2008 issue of *Neurology Now* magazine. "In the brain, music is stored in the basal ganglia and cerebellum – parts of the brain which are involved with movement." "In general, when one has a disease of the basal ganglia – such as Parkinson's – the flow of movement, speech, thought and feeling has either stopped or takes on a stuttering quality. Music can reorganize this and give people a pattern of timing and rhythm." Dr. Sacks calls music a "sort of prosthesis for the injured part of the brain". But Dr. Sacks also noted the individual needs to be actively involved with the music. Casual exposure may not provide much effect.

In research by M. Satoh and S. Kuzuhara published in *European Neurology* people with mild to moderate PD were trained to walk while mentally singing (singing to them self). Improvement was noted in the time and number of steps it took to walk a straight path and to turn. Follow up interviews found that the participants effectively used mental singing while moving in their daily lives.

In *Functional Neurology* C. Pacchetti et al. reported that Active Music Therapy had a significant effect on difficulty with movement among people with mild to moderate PD. Over time improvements were noted in mood, completion of activities of daily living and quality of life.

In other words, keep a song in your heart and your steps will be livelier.

In Frankfurt Germany W. Enzensberger et. al. studied people with Parkinson's (PWP) walking with a metronome set to 96 beats per minute. Metronome stimulation significantly reduced the time and number of steps needed to walk a test



course and diminished the number of freezing episodes. March music stimulation was less effective and rhythmically tapping on the PWP's shoulder produced negative results.

Dance the night away.

Humans have an instinct for dance. When music stirs us we absent mindedly tap our feet or drum our fingers, as an unconscious entrainment lies at the core of dance. Dance brings together movement, rhythm and gestures, dance functions with coordination in space and time in a pattern of movements.

In the July 2008 *Scientific American* positron emission tomography was used to measure changes in blood flow in the brains of amateur Tango dancers as they simulated dance with and without music or just listened to music. They found three brain regions contribute to dance in ways that go beyond simply carrying out motion.

Anterior Vermis; part of the cerebellum, it acts something like a metronome helping to synchronize dance steps to music.

Medial Geniculate Nucleus; part of the lower auditory (hearing) pathway, it underlies our tendency to unconsciously tap our toes or sway as it communicates information about rhythm to the cerebellum without "speaking" to higher auditory areas in the cortex.



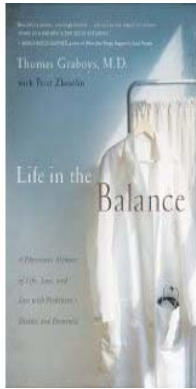
Precuneus; this region contains a sensory-based map of one's own body and helps to plot a dancer's path from a body-centered perspective.

So a dance, once rehearsed and known, is performed using lower pathways (more automatic) in the brain, those pathways that are often involved in Parkinson's Disease and those pathways that Dr. Sacks sited as being turned on by music. Afraid you might fall if you try to dance? Go jump in the pool and take a water aerobics class (see my article in the Fall 2008 NJ-APDA newsletter about water based exercise).

So the moral of the story is, if you're having trouble walking – **GO DANCING!**



New Aquatic Program Beginning!
Please see page 15 for Details!



BOOK REVIEW

Life in the Balance A Physician's Memoir of Life, Love and Loss with Parkinson's Disease and Dementia

**Authors: Thomas Graboys,
MD, with Peter Zheutlin**

(Sterling Publishing, New York 2008, 210 Pgs. \$19.95)

Book Review by Lewis Schwartz, MSW

Aptly titled this work is a courageous journey of the life experiences of Thomas Graboys, M.D., a renowned Boston cardiologist. He has been a professor at Harvard Medical School, President of the Lown Cardiovascular Research Foundation, and a medical staff member of Brigham & Women's Hospital in Boston. He was the recipient of a Nobel Peace Prize with a group of physicians, "International Physicians for the Prevention of Nuclear War."

At age 49 Dr. Graboys was at the highlight of his career enjoying a remarkable and full life when tragedy struck with the loss of his wife from colon cancer. Along with his two adult daughters, they cared for her during a very difficult two year illness until her death in 1998.

Several years later Dr. Graboys began to experience symptoms of Parkinson's disease, at about the same time that he met a "lovely caring" woman, who he later married. As for most patients with a chronic illness he was initially in denial. He finally sought treatment when the doctor became the patient after being confronted in a parking garage by a colleague neurologist when asked "who is taking care of your Parkinson's?"

Dr. Graboys vividly describes the events that he has experienced during and after the onset of his illness, Parkinson's and Lewy Body Dementia (LBD). As a Parkinson's patient myself I found his candid description of the physical, emotional and social aspects of his own personal experiences with his illness to be very familiar. He takes you on a frank trip through the trials and tribulations of his changed life in the battle with Parkinson's.

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A Study of Insomnia in Patients with PD

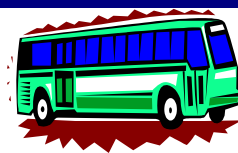
We invite PD patients who are suffering from sleep problems to find out more about this research study.

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



Bus To The Parkinson Unity Walk -April 2009

The New Jersey Chapter of the American Parkinson Disease Association (NJ APDA) will take at least one bus to the Unity Walk for Parkinson's disease in Central Park, in late April 2009 (date to be announced).

***Look for details
in the February 2009 issue of the
Parkinson Bulletin.***

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Although faced with the surrender of his beloved and highly recognized medial practice which he so deeply cared for others, he now struggles with his own everyday functioning. His story is one of remarkable revelations of his new found feelings of lack of self confidence, inadequacy, depression and resentment of increased dependency.

We, as readers and fellow Parkinson's patients, can also strongly identify with his thoughts, symptoms, and description of his sensitive relationships with family, friends, colleagues and professional caregivers. He clearly emphasizes the importance of the need for activity, exercise and hope.

One unique chapter includes the comments and observations of his family and the importance of their relationships in his support system. Another chapter effectively elaborates the important role of significant and caring friends in dealing with illness. His extraordinary openness with the effect on the sexuality of his marriage is commendable since it is rare that we see this discussed as an important facet of illness.

The final chapter, "A Life Beyond Illness" is especially meaningful since it gives a very practical prescription for "living life beyond illness". Dr. Graboys, now 63, has written in a sensitive, comprehensive and understanding way and achieves his dual mission of his continuing a desire to help the patient, family and to educate the public.

Although Dr. Graboys' own life and background is atypical of most readers there are more similarities than differences as we together face the present and uncertain future with him. He provides a realization that we are not alone or unique in our struggle to adjust to our new world. He provides hope and the importance of living each day in spite of our limitations and how we must courageously cope with the "hand we have been dealt in life."



***NJ Chapter
American Parkinson
Disease Association***

***2008-2009
Annual Giving Form***

Name _____

Phone _____

Address _____

Email _____

Donation Amount: _____

Please make check payable to:

NJ Chapter APDA

Please send to:

Benton Yip

APDA New Jersey Chapter

PO Box 2026

Edison, New Jersey 08818

Thank you so much for your generous donation!



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



***Parkinson Disease
Clinical Trials***

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

Go to www.pdtrials.org

Upcoming Educational Events and Support Group Meetings January-April 2009

RWJUH Parkinson Support Groups

Afternoon Meetings

Meets the third Thursday of the month
(unless otherwise noted).

**Time: 12:30 PM Place: Auditorium
at RWJ University Hospital,
New Brunswick, NJ**

**Meeting location is subject to change; day of meeting
please call (732) 745-7520 to confirm location.**

Thursday, January 15, 2009

Topic: Exercise and Parkinson's Disease
Speaker: David King, PT, MS

Thursday, February 19, 2009

Topic: New Medications and Parkinson's
Speaker: Mary Wagner, PharmD
Robert Wood Johnson University Hospital

Thursday, March 19, 2009

Topic: Ask the Nurse Practitioner
Speaker: Debbie Caputo, NP,
UMDNJ-RWJMS

Evening Meetings

Meets the third Wednesday of the month
(unless otherwise noted).

**Time: 7:00 PM Place: Auditorium
at RWJ University Hospital,
New Brunswick, NJ**

**Meeting location is subject to change; day of meeting
please call (732) 745-7520 to confirm location.**

Wednesday, January 21, 2009

Topic: Living Large with Parkinson's
Speaker: Dan Stark, Author of Silence of
Bunnies and Person with Parkinson's

Wednesday, February 18, 2009

Topic: Surgical Options and Parkinson's
Speaker: Dr. S. Danish, UMDNJ-RWJMS

Wednesday, March 18, 2009

Topic: Ask the Nurse Practitioner
Speaker: Debbie Caputo, NP,
UMDNJ-RWJMS



Strike Out Parkinson's Bowl-a-thon!

The NJ American Parkinson Disease Association Chapter will hold a bowl-a-thon on Sunday, March 22, 2009 at Brunswick Zone (North Brunswick NJ) from 3:00 to 5:00 PM. A minimum \$40.00 donation includes bowling, shoe rental, unlimited sodas and light snacks. Join us for fun and camaraderie. **See page 13 for full details.**



Excellence in Service Award

We are accepting nominations for the 6th Annual Excellence in Service Award. You may nominate an individual who is active in the Parkinson Community. Examples include a support group facilitator, volunteer, caregiver, or person with Parkinson's who is an inspiration to others and Parkinson advocates. **Please no political officials. Submissions are due by Friday, Feb 6, 2009**

Parkinson's Phone Support Group: Living Well With PD

This series conveniently meets by telephone! "Meeting" Monday evenings at 7:30 PM **on March 23, March 30, April 6, April 13 and April 20, 2009**

This is an opportunity to join with other people to share and discuss issues related to Parkinson's. Experts in the field will join each week. The group is open to people with PD, family, friends and caregivers. Elizabeth Schaaf will facilitate the series. Total cost: \$25.00. Guest speakers: TBA. Scholarships are available. DOROT places the calls to your home and pays for them as well. For more info, to register, call **DOROT at 877-819-9147.**



Annual People with Parkinson's and Family Conference

Annual educational symposium on **Saturday, April 4, 2009 at the Imperia, Somerset NJ**, 9:30 AM to 3:15 PM. Details in next newsletter.



Parkinson's Unity Walk

Saturday, April 2009 (date to be announced) NYC's Central Park. Please call toll free: 1-866-PUW-WALK (1-866-789-9255), fax: (609) 688-0875.; Website: <http://www.unitywalk.org>.





Powers of Attorney Questions and Answers

John J Ross, Esquire

What is a Power of Attorney?

A power of attorney is a legal document by which you designate another person to act on your behalf in the event that you are unable to take care of your own affairs as a result of physical disability or mental incapacity.

For example, through a power of attorney you can authorize your representative to handle your banking, manage your investments and pay your bills in the event you are unable to do these things yourself.

What are the Advantages of having a Power of Attorney?

Just as a Will provides for the handling of your affairs upon death, a power of attorney can provide for the handling of your affairs if a physical or mental condition prevents you from handling your financial affairs yourself.

If you become disabled, the outside world and your financial obligations do not come to a stop. Bills have to be paid. Checks have to be deposited. Financial and/or legal decisions have to be made.

What Happens If I Become Disabled or Incapacitated and I Do Not Have A Power of Attorney?

If you are unable to handle your own affairs, a court will appoint a guardian or conservator for you. This involves the commencement of legal proceedings and the hiring of lawyers, the expense of which will be paid out of your assets. In addition, a court, **not you**, will decide who handles your affairs.

Does a Power of Attorney Give Another Person the Authority to Act on My Behalf Even If No Incapacitated?

You may choose to make your power of attorney effective immediately. However, you have the option of providing that the power of attorney become effective only if you become disabled or incapacitated. You can also specify under what conditions you will be considered disabled or incapacitated for purposes of the power of attorney.

For example, you can provide that the power of attorney becomes effective only upon the furnishing

of the power of attorney.

For example, you can provide that the power of attorney becomes effective only upon the furnishing of a sworn statement from two physicians that you are incapacitated.

Do I have to Delegate All of My Decision-Making Authority to My Agent ?

Even though people often choose to delegate any and all decision-making power to their agents, you have the ability to make a power of attorney as narrow or as broad as you choose. Therefore, if your power of attorney specifies the acts which your representative is authorized to perform on your behalf, your representative can only perform those acts.

If you choose to consult an attorney, it is a good idea to ask for a specific listing of the acts that may be delegated to help you decide if you wish to limit your agent's authority in any way.

Where Do I Go to Obtain A Power of Attorney?

Power of attorney forms are available from a number of different places such as banks and legal supply stores. It is often wise to speak with an experienced attorney particularly if you wish to insure that the power of attorney will be honored by various institutions or if you wish to identify and/or limit the acts which your representative will be able to perform.

John J Ross is an attorney who specializes in Elder Law and Long-term Planning. If you have any questions about powers of attorney or any other planning needs, feel free to call his office at **(732) 294-9036**.

**A New Support Group for DBS
Patients and those considering the
surgery is looking to form in the Ora-
dell, NJ area (Bergen County).**

*Please call (732) 745-7520 if you wish
to be informed when the group begins
or if you can assist with the group.*

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**



Excellence in Service Awards Parkinson Community 2009 Nominations

We are accepting nominations for the 6th Annual NJ American Parkinson Disease Association Excellence in Service Awards. You may nominate an individual who is active in the Parkinson Community. Examples include a support group facilitator, a volunteer, caregiver or a person with Parkinson's who is an inspiration to others, and Parkinson advocates (***please no political officials***).

Please complete the below information and send, with an attached written explain (in detail) as to why this person should be a nominee. Submissions to be sent to: NJ APDA I & R Center, 120 Albany Street, Suite 360, New Brunswick, NJ 08901 Attention: Elizabeth Schaaf

Deadline for submissions is Friday, February 6, 2009.

YOUR NAME _____

YOUR ADDRESS _____

YOUR PHONE (daytime) _____

YOUR PHONE (evening) _____

YOUR EMAIL _____

NOMINEE'S NAME _____

ADDRESS _____

NOMINEE is a (ie. Caregiver, person with PD, etc) _____

***Please use another sheet of paper to explain
why they have been nominated.***

Help Strike Out Parkinson's Bowl-A-Thon 2009

Fundraiser to benefit the
NJ Chapter of the American
Parkinson's Disease Association
Brunswick Zone - Carolier Lanes
Rte 1 North, North Brunswick, N.J. 08902

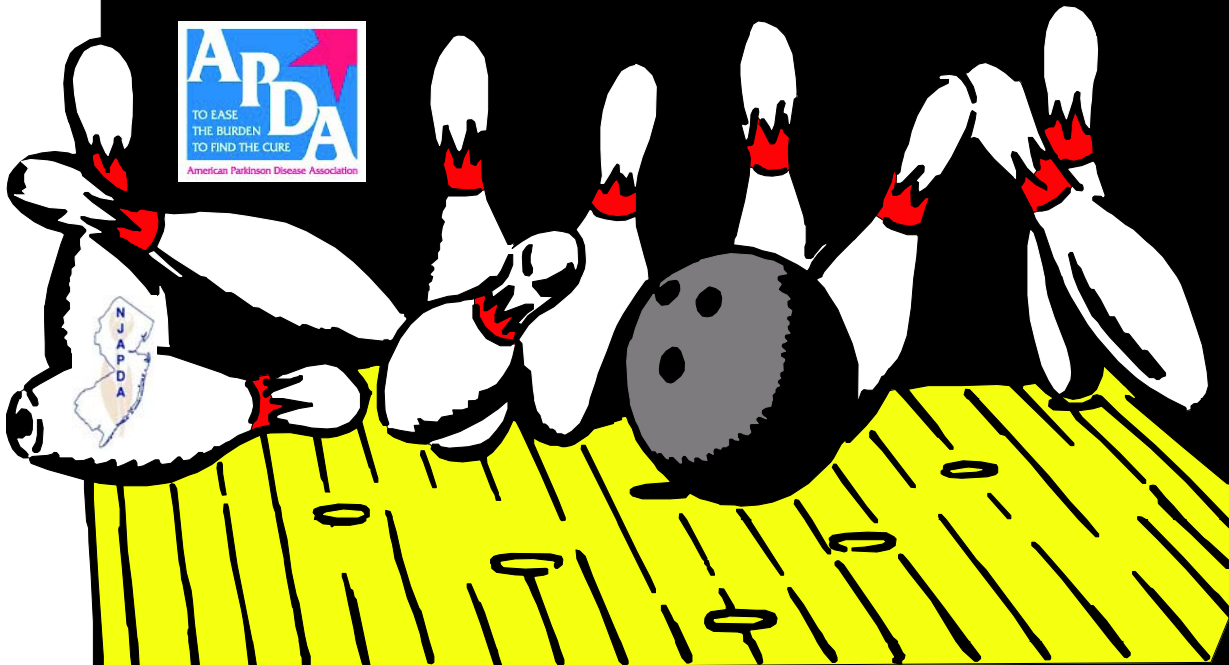
Sunday, March 22, 2009 • 3:00 p.m. - 5:00 p.m.

Fee: \$40.00 Minimum Donation per player

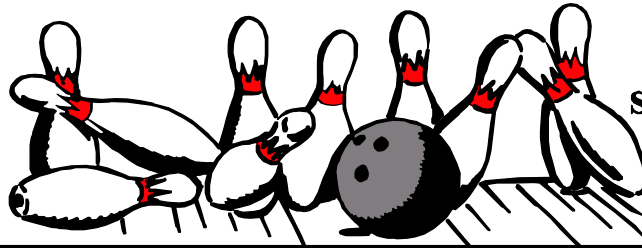
Registration forms due by March 12, 2009

Prizes for Top Raising Teams and Individuals!

Questions? Please call the NJ APDA Parkinson's Center at (732) 745-7520



BOWL-A-THON!



Sunday, March 22, 2009



STRIKE OUT PARKINSON'S

Brunswick Zone-Carolier, 790-US Route 1, North Brunswick NJ 08902

Individual/Team Registration Form

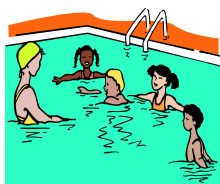
Please return by March 12, 2009 to NJ APDA I & R Center, 120 Albany Street, Suite 360, New Brunswick NJ 08901

Team Name if Applicable _____

(please note that there are 6 bowlers per lane, however you may register less than 6 members)

1.	Team Captain's Name	Address	Phone/email	Amount encl.
2.	Bowler's Name	Address	Phone/email	Amount encl.
3.	Bowler's Name	Address	Phone/email	Amount encl.
4.	Bowler's Name	Address	Phone/email	Amount encl.
5.	Bowler's Name	Address	Phone/email	Amount encl.
6.	Bowler's Name	Address	Phone/email	Amount encl.

Please call (732) 745-7520 for individual pledge sheets or go to www.apda.org/events/



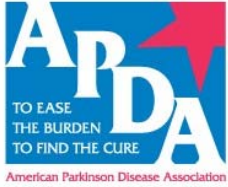
SWIM, Inc.

Accepting Applicants for Free Water Exercise Program

SWIM, Inc., a non profit volunteer organization, is accepting applications for participants in their self directed water exercise program that will be held each Monday at the **Sussex County YMCA from 1-3 PM beginning December 2008.**

The program is free to participants. Eligible participant candidates are adults with muscular impairment due to such causes as stroke, MS, accident, MD, arthritis, surgery, Parkinson's, cancer or other causes who find it difficult or impossible to exercise on land. The buoyancy of water provides an environment conducive to movement not possible on land.

SWIM, Inc. has been providing this free service at seven other locations in New Jersey since 1975. Information about SWIM, Inc. can be found on their website at <http://www.swim-inc.org> Anyone interested in applying should contact **Bob Hopkins, Sussex County Coordinator for SWIM, Inc.** at 973-729-3686 or via e mail at swismart@yahoo.com.



*New Jersey 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

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University Hospital
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(732) 745-3114-fax
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Benton Yip, President
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PO Box 2026
Edison, New Jersey 08818
njapda@gmail.com

American Parkinson Disease Association National Office
Parkinson Plaza
135 Parkinson Avenue
Staten Island, NY 10305-1425
1-800-223-2732

NJ/APDA Parkinson's Disease Information and Referral Center
One RWJ Place, Box 2601
New Brunswick, NJ 08903-2601
(732) 745-7520
(732) 745-3411-fax



ROBERT WOOD JOHNSON

UNIVERSITY HOSPITAL



SAVE THE DATES

Strike Out Parkinson's Bowl-a-thon!

Sunday, March 22, 2009

3:00 PM to 5:00 PM

Sign up today!

More details on pages 13-15

Annual People With Parkinson's And Family Educational Conference

Saturday, April 4, 2009

9:30 AM to 3:00 PM

The Imperia, Somerset, NJ

More details February 2009 Newsletter

Parkinson's Unity Walk

April 2009 (exact date-TBA)

New York's Central Park

More details February 2009 Newsletter



Parkinson Bulletin

Change or New Address

Please return to

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

PLEASE PRINT

Name _____

Address _____

Old Address (if applicable) _____

Phone _____

Email _____