

The Parkinson's Bulletin

March-May 2010

Special Conference Edition



Spring 2010



ROBERT WOOD JOHNSON
UNIVERSITY HOSPITAL



The NJ/APDA Parkinson Disease Information and Referral Center
120 Albany Street, Suite 360, New Brunswick NJ 08901
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www.njapda.org

Seniors Will Find More Options and Lower Costs for Medigap Insurance in June 2010

Sunny Rubin, Adjunct Professor, Brookdale College

Over the next two decades nearly 80 million "Baby Boomers", those born after World War II, will be applying for retirement benefits. In 2011 the first wave of this "Silver Tsunami" hits, with over 4 million boomers becoming eligible for Medicare.

With this burgeoning market, baby boomers approaching retirement are barraged with a dizzying amount of information from private insurance companies regarding Medicare and Medigap Insurance coverage that is at best overwhelming, and at worst confusing and frustrating. Not understanding your options at the time of enrollment leads many new retirees into making last minute decisions, that can result in inadequate and more costly coverage down the road. Add into this mix the fact that significant changes to Medicare Supplemental Insurance, or so called Medigap Insurance, go into effect this June, and trying to navigate the new landscape on your own is like taking a trip down the Amazon without a guide! It has never been more important to work with a professional Medicare Insurance Specialist to help sort out the confusion.

Here's what you need to know

What is driving these changes? Funding. Significant changes in MedAdvantage funding will result in the reduction of member benefits and/or increased premiums starting this year. In addition, some insurance carriers are electing to stop offering all Medicare options, or are leaving the market entirely, to offset some of their increased costs.

The bad news is that this means there will be more and more seniors in need of inexpensive Medigap Insurance to make up for the increased shortfalls in MedAdvantage. Medicare is divided into four parts, each with different coverage options, including hospital insurance (Part A), medical coverage doctor out-patient services (Part B), Medicare Advantage (Part C), and prescription drug coverage (Part D). Since the 1990's private insurance companies have been selling Medigap Insurance to supplement the coverage available in Parts A & B.

The good news is that the changes going into effect this June have increased the benefits in the Medigap plans, made them easier to comprehend, and most importantly made them more affordable.

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Spring Annual Conference
Saturday, April 10, 2010
Register today!
See page 6



Coordinator's Corner
Elizabeth Schaaf,
NJ APDA Parkinson Disease
Information and Referral Center

Dear Friends,

We are excited to announce our 2nd annual fundraiser and social event, Strike Out Parkinson's Bowl-a-thon on Sunday, March 21, 1:00 pm at Strike N' Spare in Green Brook, New Jersey. We hope you can join us. For a \$40.00 donation per person, you will receive three hours of bowling, rental of shoes, and refreshments. Registration and payment is due by Friday, March 12, 2010. You can register as an individual or you can register as a team of up to five/six people.

On Saturday, April 10, 2010 our annual conference, *Living Well with Parkinson's* will be held at The Imperia in Somerset, NJ. Please see program details on page 13 and registration information on page 6. Space is limited. Please register with form and payment by no later than April 2 to ensure your space..

Our Parkinson Caregiver Phone Educational Series will begin on Monday, April 19. Please see page 12 for registration details. This support group takes place in the comfort of your own home!

Our Painting with Parkinson's series for PWP and their caregivers, friends and family will begin on May 7; please see page 11. No prior painting experience needed. Don't miss this fun, therapeutic and inspiring series!

On April 24, the Unity Walk will take place in Central Park in New York City. If you are interested in forming team, please call the Unity Walk at **1-866-789-9255**. The NJ Chapter APDA, with the support of the Parkinson's Unity Walk will take a bus to the walk. Space is very limited; registration and payment are required Please see page 7 to register today!

I hope to see you at our upcoming events!

Kind Regards,

Elizabeth Schaaf,

Coordinator, NJ APDA Information & Referral Center



"Material presented in this newsletter is solely for information of the reader. It is not intended for treatment purposes, but rather for discussion with the patient's physician."

**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.**

**New Jersey Home Show:
 Parkinson's Exhibit
 Volunteers Needed**

March 19, 20 and 21, 2010
**Please call Peter Buckley at
 732-499-7140 to help.**



President's Notes

Vicki Collier, NJ Chapter President – American Parkinson Disease Association

Every April, Parkinson's communities worldwide join forces to promote PD awareness. Increasing public awareness and fund-raising are the two key objectives of the American Parkinson Disease Association (APDA) Chapters nationwide. Without public support we would not be able to help fund APDA's national research projects, nor would we be able to deliver the Chapter's \$20,000 annual contribution to the unique educational programs for Parkinson's patients, caregivers, and family members developed and administered by our NJ APDA Information and Referral Center Coordinator Elizabeth Schaaf. Since APDA is a privately funded non-profit organization, increasing our presence and visibility throughout NJ is paramount to our ability to continue to help individuals and families who must bravely battle the challenges presented by Parkinson's disease. In doing our part to promote public awareness this year, APDA's NJ Chapter has sought proclamations formally declaring April 2010 PD Awareness Month from the Garden State's twenty-one counties. Look for them on display at our upcoming Spring Conference on April 10 in Somerset! If you are interested in helping the NJ APDA Board with its 2010 initiatives, please email njapda@yahoo.com or call (908) 303-0090.

Poinsettias for Parkinson's December 2009

When four of the five NJ APDA Executive Board Members together have over a century of personal banking history with the same financial institution, a fundraising partnership seems inevitable. Fortunately Valerie Latham of **Affinity Federal Credit Union's** Piscataway Branch felt the same way! When Valerie learned of our charter to "ease the burden and find the cure" for Parkinson's disease, she immediately set up a brainstorming session to see how she and Affinity could help.

Within weeks, "Poinsettias for Parkinson's" was in high gear. In addition to purchasing plants to decorate NJ branches and offices, Affinity allowed our Chapter to sell poinsettias to its credit union members. The NJ Chapter thanks Affinity for its community spirit – especially the Piscataway, Hillsborough, Flemington, Cedar Knolls, and Basking Ridge locations.

The employees of Robert Wood Johnson University Hospital were equally as generous in their support of our fundraiser. I&R Center Coordinator Elizabeth Schaaf negotiated selling space in the courtyard and within just a few short hours, our poinsettias sold out! Thank you RWJUH, for this latest example of your faithful endorsement of NJ APDA's events.

Proceeds from the sale will fund PD educational programs and events run by the NJ APDA I&R center throughout the year.

Asbury Galleria Fundraiser December 2009 - January 2010



NJ APDA gratefully acknowledges the **Asbury Galleria** and its owner Kay Harris in particular for managing an education and awareness fundraiser for our Chapter. Passionate about the preservation and revitalization of Asbury Park, Kay's store features charming and varied memorabilia, and during the months of December and January included photographs and posters of the Light of Day Concert series emphasizing the quest for a cure for Parkinson's disease.

Through website, newspaper, and other local media, Kay and the Asbury Galleria team promoted \$5 donations to our APDA NJ Chapter in exchange for a chance to win four enticing prizes.

Starting with two pairs of Light of Day Concert tickets for the Paramount Theater and Stone Pony donated by Bob Benjamin, Kay then secured a framed 11x14 photograph of Bruce Springsteen at the Stone Pony donated by Rocktography's John Cavanaugh. She added one of her uniquely designed Bruce/Asbury Park t-shirts to complete the prize list.

The proceeds from this fundraiser will help offset the costs of our annual state-wide Spring Symposium at the Imperia in Somerset, NJ on April 10.



Board Member Joan deRuiter (left) and Vice President Cindy Yaros share the holiday spirit with Affinity Flemington patrons.



Roger Hedden (winner) claims prize from NJ APDA Chapter President Vicki Collier and Asbury Galleria Owner Kay Harris.

Continued from page 1

Currently it is estimated that there are over 10 million Americans with Supplemental Insurance or Medigap. Congress standardized Medigap plans in 1990 and designated all future plans A-L, with the exception of Massachusetts, Minnesota, and Wisconsin.

The Changes

Beginning this year, Medicare beneficiaries will begin to see some dramatic changes in Medigap standards and regulations. These changes were enacted by the National Association of Insurance Commissioners (NAIC) to try to reduce the costs. June will bring the addition of two new plans, Plans M & N, and the elimination of Plans H, I, & J (which contained prescription drug benefits prior to the Medicare Modernization Act). There will be a hospice benefit added to all plans. Anyone wishing to remain in their old plans will be grandfathered in. More detailed changes include:

- Elimination of Plan E (as it becomes identical to Plan D, once the Preventive Care Benefit and the At-Home Recovery benefits are removed).
- The Home Care benefit will be removed from Plan G, and the 80% coverage will be increased to 100%
- In addition to Plan A, Plans C and F must be sold by all insurers offering Plan A.
- New Plan M will have increased cost sharing (50% of Part A Deductible & no coverage for Part B deductible).
- New Plan N will have co-pays \$10.00/20.00 for Doctor visits, \$50.00 ER visits, and no coverage for Part B deductible.

In addition to these detailed changes to the plans available themselves, the GINA Requirement enacted by Congress also goes into effect this year. GINA stands for Genetic Information and Non-Discrimination Act, and it has been designed to protect seniors from being denied coverage, or having to pay higher premiums for Medigap insurance, based on information obtained from a genetic screening test.

Keep in mind that while the plans are standardized in terms of the coverages they provide and consumer protections they afford – they are

sold by individual private insurance companies, and the costs will vary from company to company and state to state.

You are not required to make any kind of change to your existing plan, and you may or may not be affected by these changes – but transition standards have been put in place which may permit your insurance company to allow you to switch plans, and maybe even save some money without losing any benefits. Also, the modernization program gives insurance companies offering Medigap plans the opportunity to add increased benefits such as for wellness-programs, gym memberships, and eyeglasses.



Plans A, B, C, the NAIC, GINA reform -all these letters can begin to sound like so much “alphabet soup” – and these changes can be confusing and frustrating, but keep in mind that they have all been designed to provide seniors with more rights and more coverage, at a lower cost.

If you are not sure how these changes affect you, or you have questions, please call your insurance carrier, speak to your agent, or seek the advice of a qualified Medicare Specialist Insurance professional.

Sunny Rubin

Adjunct Professor

Email questions: srubin1028@aol.com



CHECK OUT OUR WEBSITE!

www.njapda.org

LEARN ABOUT

***Upcoming Events
Support Groups
Order Free Literature
How to Donate
View the 2009 Spring
Conference Online!*****

***Download Past Newsletter Articles
And More!!***



The Treatment of Multiple System Atrophy

Lawrence I. Golbe, MD

Professor of Neurology, UMDNJ-RWJMS



Multiple system atrophy (MSA) is one of the so-called “Parkinson-plus” disorders or “atypical parkinsonisms.” It is not a form of Parkinson’s disease (PD), but the two disorders do share outward features such as slow movement, impaired balance, difficulty in organizing thoughts, and soft speech. The major differences are that MSA, relative to PD, displays much less tremor, progresses more quickly, develops its balance problem earlier in the course and responds much less well to levodopa and other PD drugs. The average age at appearance of the first symptoms of MSA is only 53, while for PD it is 59.

One of the most important features of MSA is impaired function of the “autonomic nervous system,” parts of the brain, spinal cord and nerves that control such involuntary functions as blood pressure, heart rate, actions of the intestines and bladder, erectile activity and breathing activity. PD may impair most of these too, but to a much lesser degree.

Another important feature of MSA and one that does not occur at all in PD is impairment of the cerebellum. Located in the back of the brain against the floor of the skull, the cerebellum helps coordinate and regulate voluntary movement. Its impairment often gives one a drunken appearance, with difficulty aiming the eyes, slurred speech, wavering hand movement and staggering gait.

MSA emphasizing the autonomic problem was once called “Shy-Drager syndrome.” When it features the cerebellar problem it was called “sporadic olivopontocerebellar atrophy” and when it featured the parkinsonian slowness and stiffness, it was called “striatonigral degeneration.” In 1989 the commonalities among these at the level of the brain cells was discovered and the overall disorder was given its present name. The treatment of MSA, as you would guess from this list of symptoms, can get complicated.

Unfortunately, the two most important features of MSA, the balance problem and the cerebellar problem, are not presently treatable with medication. These may respond to physical therapy, which is worth a try in every case, but the principal benefit here are tips in adapting the home and in using walking aids.

On the other hand, the muscle stiffness and slowness of MSA may respond usefully to levodopa/carbidopa, the mainstay of PD treatment. To the extent that falls are the result of slowness to respond and compensate for a sudden loss of balance, such medication may reduce the frequency of falls. The main side effect of levodopa/carbidopa in MSA is worsening of existing low blood pressure. Less common side effects can be hallucinations, confusion and involuntary movements. The low blood pressure and heart rate problem in MSA is most noticeable when assuming a standing position, producing lightheadedness and sometimes fainting. Treatment begins with making sure you are receiving plenty of water and sodium. Of course, people with certain conditions of the heart or other organs should restrict water and sodium. Also helpful are non-drug measures such as wearing pressure hose, raising the head of the bed six inches (by placing blocks under two legs of the bed, not by bending the mattress or using pillows) and pausing for a minute in the sitting position during the transition from supine to standing. Many drugs can raise the blood pressure, but the three most commonly prescribed for people with MSA are fludrocortisone (brand name Florinef), midodrine (Pro-Amatine) and physostigmine (Mestinon). The first two have the potential side effect of raising the blood pressure excessively when one is lying flat. The third does not have this problem, but is not as consistently effective as the first two.

The urinary urgency and incontinence of MSA should be evaluated by a urologist with experience in neuro-urology. Sometimes a condition is found that would respond to an antibiotic, surgery or pelvic floor exercises. In most cases, however, the urologist will prescribe treatment with one of the popular drugs used to inhibit bladder emptying such as oxybutinin (Ditropan) or tolterodine (Detrol). These drugs, however, can aggravate constipation. Ancillary measures to reduce bathroom trips during the night include avoiding all fluids between supper and bedtime and tilting the bed up to reduce blood flow to the kidneys during sleep.

The constipation of MSA should receive careful attention. It is treated no differently from constipation of any cause. The basics are plenty of fluids, light exercise, fiber in the form of supplements and high-fiber foods and avoidance of low-fiber foods. A stool softener such as docusate given one to three times a day can help greatly and is not habit-forming. Mild stimulants such as Milk of Magnesia can be used occasionally, as can harsher stimulants, laxatives or enemas.

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*Living Well with Parkinson's
Spring Conference for People with Parkinson's and
Their Families*

Saturday, April 10, 2010

9:30 am to 3:15 pm

The Imperia, Somerset, NJ

Please send to : NJ APDA I & R Center, 120 Albany Street, Suite 360,

New Brunswick NJ 08901

(program details on page 13)

*Space is limited; please register by returning completed form and payment
no later than April 2, 2010 to ensure your space.*

You will receive confirmation and directions to The Imperia once you register.

REGISTRATION FORM

Please print

Name (s) : Please circle one

- _____ Menu selection: Chicken Francaise Grilled Salmon Eggplant Rollatini
- _____ Menu selection: Chicken Francaise Grilled Salmon Eggplant Rollatini
- _____ Menu selection: Chicken Francaise Grilled Salmon Eggplant Rollatini
- _____ Menu selection: Chicken Francaise Grilled Salmon Eggplant Rollatini

Address to send confirmation letter and directions:

Email _____ Phone (daytime) _____

Amount enclosed (\$30.00 per person) _____

If you are a support group leader or co-facilitator, please check here ____ YES

How long have you been overseeing or assisting the group? _____

Your Name _____ Group name/location _____

*Checks made payable to Robert Wood Johnson University Hospital
Subject: PD Conference-April 10, 2010*



Bus Available To Take Walkers To The Unity Walk!

Saturday, April 24, 2010

Thanks to the support of the NJ American Parkinson Disease Association Chapter, we will take a bus to the Unity Walk for Parkinson's disease in Central Park on Saturday, April 24, 2010. We hope you will join us! For more information on the walk itself, please call (1-866-789-9255) or go to <http://www.unitywalk.org>. Informational booths open at 10:00 am; program starts at 12:30 pm; walk begins at 1:00 pm. The bus will leave NYC by 3:15 pm. **Please note that seats can't be held without registration (below) and payment. Space is limited. Register today!**

Please bring a bag lunch with you; only snacks and water will be provided on the bus.

BUS Routes

Sears

North Brunswick NJ

Departs at 8:15 am

Robert Wood Johnson-Rahway

Rahway, NJ 07065

Departs at 9:00 am

Mountainside Hospital

Montclair, NJ 07402

Departs at 9:45 am

For more information, please call (732) 745-7520.

Space is limited; please send in your registration form and payment.

Spaces can't be held without payment.

Unity Walk Bus Registration

**Please complete and send to: NJ APDA Parkinson I & R Center
120 Albany Street, Suite 360, New Brunswick, New Jersey 08901
(732) 745-7520 (office)**

Name (s) _____

Address _____

Phone (daytime) _____ Cell phone (for day of event-must have) _____

Email _____

Amount Enclosed (\$15.00 Per Person-includes tip for driver) _____

Please make checks payable to the NJ Chapter, APDA

Departing from (please circle one) Bus Route

1. Sears-North Brunswick

2. RWJUH @ Rahway

3. Mountainside Hospital

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Erectile difficulty (ED) can be the first symptom of MSA in men, occurring years before any other. It is treated like ED of any other cause, but the standard medications can reduce blood pressure, which means they should be used cautiously in MSA.

The night-time breathing problem of MSA can take the form of partial obstruction producing only noisy breathing, or the more serious obstructive sleep apnea. A neurologist with special training in sleep neurology or an internist specializing in sleep medicine can prescribe a machine to provide extra air pressure during inhalations. Called "continuous positive airway pressure" (CPAP), it involves a mask worn during sleep. Rarely, a tracheostomy (a hole in the windpipe at the front of the neck) is necessary for people who cannot tolerate the mask.

Another sleep-related problem of MSA (which can also occur in PD) is "rapid-eye-movement behavioral disorder" (RBD). This is where dreams are acted out, sometimes very loudly or violently, usually without the awakening the patient. The tranquilizer clonazepam (brand Klonopin) taken at bedtime prevents RBD in most cases and is appreciated greatly by the bedpartner.

In some cases, swallowing becomes difficult to swallow and thin liquids start to enter the windpipe during swallowing. Lest this cause lung irritation and pneumonia, evaluation by a speech/swallowing pathologist, guided by the result of an x-ray movie called a "modified barium swallow," can provide advice on how to change the diet or eating habit. If that fails, a tube can be inserted through the wall of the stomach and abdomen for feeding pureed foods. Called a "percutaneous endoscopic gastrostomy" (PEG), the tube is clamped off when not in use and can be easily managed by a family member after a little training. Insertion of a PEG is a minor procedure, but it requires careful discussion among patient, family and physician.

Could MSA be prevented or cured? MSA is a rare condition, affecting only about four persons per 100,000 population, far fewer than the 200 for PD or the 800 for Alzheimer's disease (AD). As an "orphan disease," MSA receives little attention from drug companies. In nearly all "neurodegenerative disorders"

such as these, a specific protein forms abnormal clumps in brain cells. In 1999, researchers discovered that the clumps in PD and MSA were made of the same protein. This means that a similar set of abnormal events may occur in the brain cells in the two diseases. So the massive research effort currently in progress against PD may apply to MSA as well. Recent research even suggests that neurodegenerative disorders with different protein clumps such as PD and AD may have enough in common that one prevention may benefit both. So there is realistic hope that the next few years could bring a prevention or cure of MSA.



Where to Find Support for MSA

By Nancy Josephson

Until recently, information on Shy-Drager Syndrome/ Multiple Syndrome Atrophy (SDS/MSA) was difficult to locate. Helpful resources for patients--and for families of those affected--were few and far between.

Today, that's changing. There is still no cure for this rare and devastating disorder that is known to cause progressive damage to the central and autonomic nervous system. But there are resources to help you navigate this unfamiliar territory.

The National Institute of Neurological Disorders and Stroke at the National Institutes of Health (NIH) in Bethesda, Maryland, provides an informative online fact sheet at www.nih.gov/disorders/msa/detail_msa.htm. The site offers a brief overview of the signs and symptoms of MSA (fainting, bladder control problems and loss of balance), along with general information about who MSA affects (men and women primarily in their 50s) and the course of the disease itself (it advances rapidly over a 9 or 10 year period). The site also provides a brief discussion about the difficulty of obtaining an early diagnosis because symptoms are similar to those of Parkinson's disease and other movement disorders. For general information about the brain, brain research and brain disorders check out www.ninds.nih.gov. For answers to specific questions about brain disorders contact the Institute's Brain Resources and Information Network (BRAIN) at P.O. Box 5801, Bethesda, Maryland, 20824 or call 800-352-9424 for information.



The Rochester, Minnesota-based Mayo Clinic provides a helpful and user-friendly online guide to MSA at www.mayoclinic.com/health/shy-drager-syndrome/DS00989/DSECTION=symptoms.

The clinic briefly notes that there are several current theories on the causes of MSA, including heredity and environmental toxins. However, it also states that there is no

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Where to Find Support for MSA
Continued from page 8

evidence yet to support these theories. The site catalogs more than 15 different symptoms of MSA, and lists several common tests for the disorder (including the tilt table test, the sweat test and others to assess bowel and bladder function). The clinic's experts also suggests several easy-to make lifestyle and dietary changes to help manage signs and symptoms of MSA.

Founded in 1989, the SDS/MSA Support Group (P.O. Box 279615, Coupland, Texas 78615) provides invaluable information and support for patients, caregivers, family members and medical professionals who are involved in the care or treatment of individuals with multiple system atrophy. Services include a FAQ sheet, local and national support groups, a quarterly newsletter and a toll-free hotline (866-SDS-4904). Go to www.shy-drager.org, for links to drug trials, referrals to experienced doctors and clinics as well as additional information.

The last few years have seen a sharp rise in the number of books, movies and online blogs exploring the lives of patients and families facing down MSA and other movement disorders. Among them: The widely-praised national best-seller *Saving Milly: Love, Politics, and Parkinson's Disease* by Morton Kondracke (www.ballantinebooks.com/BRC). Also, Janet Edmunson's *Finding Meaning with Charles: Caregiving with Love Through a Degenerative Disease* (www.findingmeaningwithcharles.com) Information about the DVD *Sophie's Search for a Cure*, one woman's battle against MSA and her efforts to raise awareness of the disease and funds for research, is available at www.rainlightfilms.com For more insight into the nature of this disease look online. Some patients and family members have turned to online diaries to reveal raw insights and shed a rare light on this devastating disorder. You Tube also features several amateur videos that explore the experience of living with MSA.


Nancy Josephson is a writer/editor who specializes in health. Her articles have appeared in numerous magazines.



On March 21, 2010, the APDA NJ Chapter will be hosting its second annual *Strike Out Parkinson's* bowl-a-thon fundraiser. Your participation is crucial in raising funds for our Information and Referral Center educational and support group programs from which we all benefit. Please help our cause by bringing friends and family to this fun-filled afternoon of bowling and camaraderie. Food and Prizes included! Register before February 26 and be eligible to win a \$25 gift card. If you can't make it but would like to contribute, please send your donation to: **APDA NJ Chapter, 120 Albany St, Suite 360, New Brunswick, NJ 08901. Questions- Tel: 732 745-7520. More details on pages 14 and 15.**

We hope to see you there!

Strike Out Parkinson's Bowl-a-thon
Sunday, March 21, 1 - 5 pm
Strike and Spare Lanes
380 US Highway 22 (West)
Green Brook, NJ



Interested in volunteering with our NJ APDA Chapter?

We could use your help and talent!
Please call 908 303-0090 or email
njapda@yahoo.com.



Lee Silverman Voice Treatment LSVT® LOUD

Sarah Sheridan, MA CCC SLP, Kessler Institute for Rehabilitation

“If you don’t talk loud enough – people stop listening.”

“If I have no voice, I have no life.”

These are direct quotes from individuals who live with Parkinson disease (PD). They reflect the devastating impact that a speech and voice disorder can have on the quality of a person’s life.

Research shows that 89% of people with PD experience speech and voice disorders, including soft voice, monotone, breathiness, hoarse voice quality, and imprecise articulation. As a result, people with PD report that they are less likely than healthy individuals in their age group to participate in conversations or to have confidence in social settings.

Why do people with PD have speech and voice problems?

1. Motor system: the inadequate muscle activation that leads to bradykinesia (slow movement) and hypokinesia (small movement) in the limbs can also trigger a speech disorder. For speaking, deficits in muscle activation can result in reduced breath support, reduced vocal loudness, and reduced clarity of speech.
2. Sensory system: changes in the sensory feedback system may cause people with PD to be unaware that their speech is getting softer and more difficult to understand. People with PD may say that his or her spouse needs a hearing aid. People with PD may complain that they feel as if they are shouting when they bring their voice to normal loudness. Because of these sensory changes, individuals with PD may find it easier to respond to external cues (in other words, instruction from someone else to “speak loudly”) than to respond to internal cues (telling themselves to use a louder voice).

These problems may be frustrating for the person with PD and his/her families. The person with PD feels that he/she is speaking loudly enough and do not understand why people ask them to repeat themselves. And because the speech loudness responds to external cues, the family may feel as if the person with PD can be louder and clearer if only he/she would try harder.

if only he/she would try harder.

What can help speech and voice problems in individuals with PD?

LSVT® LOUD improves vocal loudness by stimulating the muscles of the voice box (larynx) and speech mechanism through a systematic hierarchy of exercises. Focused on a single goal – “speak LOUD!” – the treatment improves respiratory, laryngeal, and articulatory function to maximize speech intelligibility. It does not train people for shouting or yelling; rather, the treatment uses loudness training to bring the voice to an improved, healthy vocal loudness level with no strain.

Over the past 15 years, studies supported by the National Institute for Deafness and other Communication Disorders (NIDCD) of the National Institutes of Health have demonstrated that LSVT® LOUD is an effective speech treatment for people who live with PD. Those who have used it have improved their vocal loudness, intonation, and voice quality, and have also maintained these improvements for up to two years after treatment. Other research studies have documented the effectiveness of LSVT® LOUD in addressing disordered articulation, diminished facial expression, and impaired swallowing. Brain imaging studies have documented evidence of positive changes in the brain following administration of this therapy.

How does LSVT® LOUD work?

The program is administered in 16 sessions over a single month (four individual 45-60 minute sessions per week). This mode of administration – much more intensive than conventional programs – is consistent with theories of motor learning and skill acquisition, as well as with principles of neural plasticity (in other words, the capacity of the nervous system to change in response to signals). In addition to stimulating the motor speech system, the treatment incorporates sensory awareness training to help individuals with PD recognize that their voice is too soft and making them comfortable with their new voice.

Continued on page 11

**Lee Silverman Voice Treatment
Continued from page 10**



Adapted from article by Lorraine Ramig, Ph.D., CCC-SLP, Cynthia Fox, Ph.D., CCC-SLP, and Becky Farley, Ph.D., PT

How do I get more information?
How do I find a clinician who is certified in LSVT® LOUD?

Go onto the LSVT® LOUD website, at: www.LSVTGlobal.com to find a certified LSVT therapist near you.

Or, contact:
Sarah Sheridan, MA CCC SLP
Kessler Institute for Rehabilitation
Office- (973) 414-4751

DBS Support Group

The North Jersey Deep Brain Stimulation (DBS) Patient Support Group will begin on Wednesday, March 10 at 7 pm in Oradell, NJ. This group is for patients with DBS and caregivers. Please RSVP by March 1 to Alexis at 201-342-2550.



**Parkinson Disease
Clinical Trials**

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

Go to www.pdtrials.org



**Painting
For Peace of Mind
Painting Series**

**Join us for this fun and interactive art series with
Sandy Frank, Senior Advisor**

**Fridays, May 7, 21, and 28
(Please note dates differ from the
Winter Newsletter)
1:00 PM to 3:00 PM**

**Location: Robert Wood Johnson
University Hospital, New Brunswick**

No prior painting experience needed!

**Fee: \$35.00
includes painting supplies**

**Please register by Friday, April 16, 2010
(see below)**

**May Painting Series
Registration Form**



Name (s) _____

Address _____

Phone _____

Email _____

Amount enclosed _____

**Please return to the NJ APDA Parkinson Information and Referral Center, 120 Albany Street, Suite 360, New Brunswick, NJ 08901; please call (732) 745-7520 with any questions. Checks made payable to:
NJ APDA Chapter
Subject-Spring Art Classes**



Upcoming Educational Events and Support Group Meetings Spring 2010-March-May

RWJUH PD Support Groups

Afternoon PD Support Group

Location: RWJUH, New Brunswick

12:30 pm to 2:30 pm. Hospital Auditorium

Thursday, March 18, 2010

Topic: Preventing Falls: What You Need To Know-

Speaker: Debbie Caputo, APN, UMDNJ-RWJMS

Thursday, April 15, 2010

Topic: Medicare Part D and Medicare

Modernization Act

Speaker: Sunny Rubin, Adjunct Professor of Medicare, Brookdale College

Thursday, May 20, 2010

Topic: Living Daily with Parkinson's Disease

Speaker: Helen Hunter, ACSW, LSW

Evening Support Group

Location: RWJUH, New Brunswick

7:00 pm to 9:00 pm Hospital Auditorium

Wednesday, March 17, 2010

Topic: Ask the Nurse Practitioner about PD

Speaker: Debbie Caputo, APN, UMDNJ-RWJMS

Wednesday, April 21, 2010

Topic: Medicare Part D and Medicare

Modernization Act

Speaker: Sunny Rubin, Adjunct Professor of Medicare, Brookdale College

Wednesday, May 19, 2010

Topic: Living Daily with Parkinson's Disease

Speaker: Helen Hunter, ACSW, LSW

Dorot's Caregiver's Connections

Presents: Caring For A Loved One With Parkinson's Disease

This series is for caregivers only and conveniently meets over the telephone..

It will occur on Monday evenings at **7:30 pm, April 19, 26, May 3, and May 10, 2010**. This is an opportunity to join with other people caring for a loved one with PD. Cost is \$25.00. There will be 2 open sessions for sharing and discussion among members. Guest speaker topics include: Ask the Neurologist, Coping with the Emotional Aspects of PD and How to Manage the Non-Motor Symptoms of PD (depression, anxiety, sleep disorders, etc). Please call Fran Rod with DOROT at (973) 763-1511.



Strike Out Parkinson's Bowl-a-thon!

The NJ American Parkinson Disease Association Chapter will hold a bowl-a-thon on **Sunday, March 21, 2010 at Strike N' Spare in Green Brook, NJ**

from 1:00 pm to 5:00 pm. A minimum \$40.00 donation per person includes bowling, shoe rental, pizza, soda, and light snacks. Join us for fun and camaraderie. Space is limited; please register by March 12. **See page 14 and 15 for further details. For individual pledge sheets, please go to www.njapda.org or call (732) 745-7520 with any questions. Proceeds help support the NJ APDA I & R Center's events and programs.**



Living Well With Parkinson's Spring Conference

The Spring Annual Symposium for people with Parkinson's (PWP) and caregivers will be held on **Saturday, April 10, 2010 9:30 am to 3:15 pm** at The Imperia in Somerset, NJ. Fee: \$30.00 per person including continental breakfast and lunch. Space is limited. Please return registration form on page 6 with payment by April 2 to ensure your seat. Please see program details on page 13.

Bus to the Unity Walk The NJ APDA Chapter will take one bus to the walk to the walk on Saturday, April 24, 2010 in NYC. We hope you can join us! The three stops are: Sears in North Brunswick, Robert Wood Johnson University Hospital in Rahway, and Mountainside Hospital in Montclair. Seats are \$15.00 per person which includes driver's tip. Please bring a bag lunch with you. Space is limited! Your registration form and payment will secure your space. **Please see page 7 for registration. Spaces cannot be held without payment.**

Painting With Parkinson's For Peace of Mind

Fridays, May 7, 21, and 28 from 1:00 pm to 3:00 pm.

Join us for this interactive painting class for people with Parkinson's and caregivers. This three week series is \$35.00 per person, which includes guided instruction and all paint materials. **Please call the center at (732) 745-7520 to register today!**





*Spring Living Well With
Parkinson's Conference*
Saturday, April 10, 2010
8:30 AM to 3:15 PM

- 8:30 AM to 9:20 AM** *Registration, Exhibits and Breakfast*
- 9:30 AM to 9:35 AM** *Welcome & Introductions*
- 9:35 AM to 10:35 AM** *Living with Parkinson's: Lessons of Hope*
Dave Iverson, producer, writer and anchor
- 10:35 AM to 10:50 AM** *Break*
- 10:50 to 12:00 PM** *Coping with Parkinson's Disease: A Team Approach for Optimal Health*
Dr. Claire Henchcliffe
Movement Disorder Specialist
- 12:00 PM to 1:30 PM** *Lunch and Presentation of Service Awards, Raffle*
- 1:45 PM to 2:00 PM** *Parkinson's Unity Walk*
Helaine Isaacs, Event Director
- 2:05 PM to 3:15 PM** *Parkinson's Disease & Activities of Daily Living (ADL)*
John Argue, author and teacher

SPACE IS LIMITED for the conference; please send completed registration form (page 6) along with payment by no later than April 2 to ensure your spot.



DIRECTIONS

The Imperia, Somerset, New Jersey

RT. 287 (North or South)

Exit 10 Rt. 527 South Easton Avenue. Imperia will be 1/4 mile on your right.

NJ TURNPIKE (North or South)

Exit 10 to Rt. 287 North. Exit 10 Rt. 527 South Easton Avenue. Imperia will be 1/4 mile on your right.

GARDEN STATE PARKWAY (South)

Exit 129 for 287 North. Exit 10 Rt. 527 South Easton Avenue. Imperia will be 1/4 mile on your right.

GARDEN STATE PARKWAY (North)

Exit 127 for 287 North. Exit 10 Rt. 527 South Easton Avenue. Imperia will be 1/4 mile on your right.

RT. 22 OR RT. 78 (East or West)

To Rt. 287 South. Exit 10 Rt. 527 South Easton Avenue. Imperia will be 1/4 mile on your right.

**Living Well with Parkinson's
Conference Speakers**



John Argue has been teaching movement and voice for people with Parkinson's disease since 1985. His approach reflects his extensive training in yoga, tai chi, dance, and drama. Techniques of The John Argue Method™ are presented in the book *Parkinson's Disease and The Art of Moving* and its *Video Companion* in VHS or DVD. John is a frequent speaker at symposia and conferences for healthcare professionals, fitness and exercise teachers, and individuals and families whose lives are affected by Parkinson's disease.



Claire Henchcliffe, M.D., D.Phil., is Assistant Professor of Neurology at Weill Cornell Medical College, and directs the new Weill Cornell Parkinson's Disease and Movement Disorder Institute. She received her DPhil., in molecular biology at Oxford University, UK, and after a period of basic neuroscience research at Cambridge University, UK, and UC Berkeley, she graduated medical school at Columbia University, and continued there in neurology residency, going on to a movement disorders fellowship with Dr. Stanley Fahn. She is a Parkinson's Study Group investigator in the upcoming NIH-funded study "Effects of Coenzyme Q₁₀ in Parkinson's Disease - Phase 3".

Helaine Isaacs is the Parkinson's Unity Walk Event Director, responsible for overseeing the logistics of the Parkinson's Unity Walk, and to help raise funds for research for Parkinson's disease by developing and maintaining relationships with participants, volunteers, sponsors, and foundations that are associated with the Walk.



FRONTLINE **David Iverson** has been a producer, writer and anchor for public broadcasting for nearly 30 years. He co-produced, directed, wrote and reported the 2009 PBS Frontline documentary "My Father, My Brother and Me," which profiled his family's struggle with Parkinson's disease. Other recent productions include a national special for PBS called Kids and Divorce: For Better or Worse and the national follow-up to The American Experience episode Two Days in October. Iverson was the writer, narrator, co-producer and executive producer of the national Emmy award winning PBS documentary "The 30 Second Candidate".

Help Strike Out Parkinson's Bowl-A-Thon 2010

Fundraiser to benefit the
NJ Chapter of the American
Parkinson Disease Association
Strike N' Spare Lanes
380 US Highway 22, Green Brook, NJ 08812

Sunday, March 21, 2010 • 1 p.m. - 5 p.m.
Fee: \$40.00 Minimum Donation per player (adult)
\$25.00 Minimum Donation per player (12 and under)
Donation includes shoe rental, pizza, and snacks.

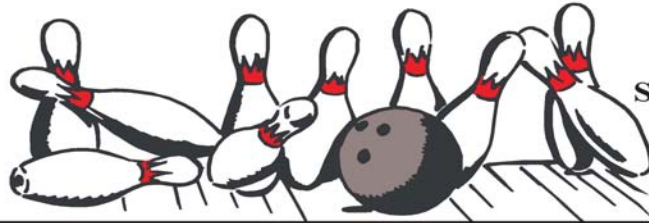
Registration forms due by March 12, 2010

*Questions? Please call the NJ APDA Parkinson's Center at (732) 745-7520
www.njapda.org/events*



If you are unable to attend the bowl-a-thon but would like to make a donation,
please make check payable to: NJ APDA Chapter and send to NJ APDA I & R Center
120 Albany Street, Suite 360, New Brunswick, NJ 08901

BOWL-A-THON!



Sunday, March 21, 2010



STRIKE OUT PARKINSON'S

Strike N' Spare Lanes 380 US Highway 22, Green Brook, NJ 08812

Individual/Team Registration Form (up to 6 bowlers per lane)

Please return by March 12, 2010 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 listed below, however you may register fewer 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.njapda.org/events



15th PARKINSON'S UNITY WALK **COMMUNITY & EDUCATION DAY**

FUND THE RESEARCH • FIND THE CURE

APRIL 24, 2010

**Be Part of the Largest Grassroots
Fundraising Event in the Country for Parkinson's Disease Research**

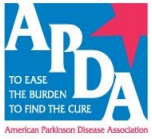
- Last year at the 14th Annual Parkinson's Unity Walk, 10,000 people attended in New York City's Central Park
- Participants from 50 States and 17 foreign countries came together and raised \$1.8 million for research
- 100% of all donations go towards Parkinson's disease research

FOR MORE INFORMATION

www.unitywalk.org

info@unitywalk.org

866-PUW-WALK (789-9255)



*New Jersey Parkinson Disease Association
Information & Referral Center*

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UMDNJ/RWJMS

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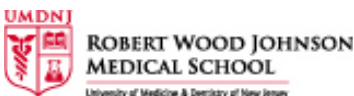
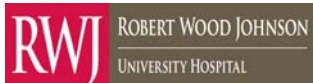
**American Parkinson Disease
Association**

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



REGISTER TODAY!

Strike Out Parkinson's Bowl-a-thon!

Sunday, March 21, 2010
Strike N' Spare, Green Brook, NJ
1:00 PM to 5:00 PM
See pages 14 and 15.

Living Well With Parkinson's Conference

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9:30 AM to 3:15 PM
The Imperia, Somerset, NJ
See pages 6 and 13.

Parkinson's Unity Walk

Saturday, April 24, 2010
New York's Central Park
See pages 7 and 15.
<http://www.unitywalk.org>



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 _____

New Address _____

Old Address (if applicable) _____

Phone _____

Email _____