

# Parkinson's Report

A publication of the American Parkinson Disease Association Massachusetts Chapter and the APDA Information & Referral Center at Boston University Medical Center.

Winter 2009

Published by the  
American Parkinson  
Disease Association  
Information & Referral  
Center at Boston  
University Medical Center

72 East Concord St, C3  
Boston, MA 02118  
800-651-8466 or  
617-638-8466  
Fax: 617-638-5354  
[www.apdama.org](http://www.apdama.org)

Editors:  
Cathi A. Thomas RN, MS  
Debora Case

Marie Saint-Hilaire MD  
Medical Director

This publication is  
supported by the APDA  
Massachusetts Chapter

APDA National Office  
135 Parkinson Avenue  
Staten Island, NY 10305  
800-223-2732  
[www.apdaparkinson.org](http://www.apdaparkinson.org)

This newsletter is in-  
tended solely to provide  
you with information on  
Parkinson's disease. You  
should not make any  
changes to treatment  
without first discussing  
them with your healthcare  
provider.

## Coordinator's Notes

Cathi A. Thomas RN, MS

Greetings and Happy New Year! We are pleased to provide you with the latest news from the APDA Information and Referral Center at Boston University Medical Center and the APDA Massachusetts Chapter. Please take this opportunity to read about recent activities and save the date for our programs and events in 2009.

Many of you have had an opportunity to meet or speak with Debora Case, a dedicated staff member here at the APDA Information & Referral Center. I would like to take this opportunity to congratulate Debbie on a very successful first year. Debbie has worked tirelessly on our telephone helpline. She is always willing to assist an individual, family member, health care provider, support group leader or anyone requesting information on Parkinson's disease. She has improved our technology here at the Center so that information is disseminated in a more organized and efficient manner. Debbie graduated with a B.A. from Wheaton College where she majored in mathematics and minored in psychology. Prior to joining the Center, she was involved in community outreach, rehabilitative services, and support for the mental health community through non-profit organizations. She has previous experience as a research assistant in psychology, computer science, and environmental biology.



*Debora Case*

I would like to thank all who were involved in our fall programs. In October, we held our second annual "Good Start Program" at Boston University's Sargent College. This three part series provided information presented by a team of experts to newly diagnosed individuals and families. Topics included diagnosis of Parkinson's disease, medical and rehabilitative treatment strategies, and accessing support services in MA. We will repeat this program in October 2009 (see calendar).

Two major events took place in November. The first was the APDA Support Group Leader's Conference in Sturbridge, MA. Twenty-nine Massachusetts leaders met with others from New England to receive information from Susan Ottenheimer, LCSW, and David L. Snow, PhD, Yale faculty members representing the Ct Self-Help Network. They provided a comprehensive program of leadership training. I would like to acknowledge the financial support of the APDA CT

*Continued on next page*

*Continued from front page:*

and MA Chapters that provided funds and other program costs for our volunteer support group leaders to attend. We are so fortunate here in MA to have 42 leaders plus many other volunteers provide an opportunity for people to get support very close to home. Thank you for your service.

Over 450 people participated in the APDA New England Parkinson Symposium held at the Sturbridge Host Hotel on Friday, November 13th and 14th. Our planning committee and wonderful volunteers provided a well organized and enjoyable event. Participants had an opportunity to attend lectures presented by leading experts in the care and support of individuals and families affected by Parkinson's disease. Special thanks to our dedicated speakers. In addition, 27 vendors provided information on useful products, care facilities, and supportive services. Many reported there was an opportunity to network and meet other people as well as share personal experiences at lunch and in-between sessions.

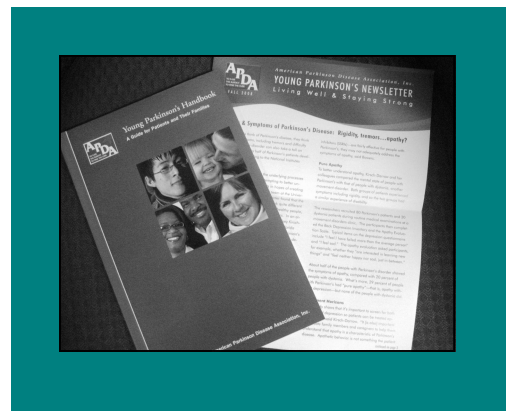


*2008 APDA New England Parkinson's Disease Symposium*

New initiatives at the Center include the development of support groups in Brookline, Sturbridge, and a Young Onset PD Support Group in Western, MA. I have met with individuals who will facilitate these groups and am excited to report program planning has begun. Visit [www.apdama.org](http://www.apdama.org) for regular updates.

## Young Onset Parkinson's Center

The American Parkinson Disease Association has established a **Young Onset Center** with a full-time director dedicated solely to supporting young individuals and their families. The Center is located at Glenbrook Hospital in Glenbrook, Illinois. Please feel free to contact the director, Julie Sacks, LCSW at 877-223-3801, [apda@youngparkinsons.org](mailto:apda@youngparkinsons.org) or visit the young onset center website: [www.youngparkinsons.org](http://www.youngparkinsons.org). There is also a new Young Onset Parkinson's Handbook available. Contact the Young Onset Center or the APDA Information & Referral Center at 617-638-8466 to learn more about this publication.



## Letter from the Chapter President

Keith J. Ciccone

Dear Friend,

I am sure by now most of you are looking forward to the coming of spring. Each year as I see the tulips peek through the snow, I am reminded of the hope in finding a cure for Parkinson's disease. The tulip, as you may or may not know, is the symbol for Parkinson's disease. Before I share the events planned for 2009, I am delighted to share the many ways in which our community has shown support this past fall.

Our Annual APDA Putt for Parkinson's Celebrity Golf Tournament was once again successful raising over \$25,000. Over the past thirteen years this event has contributed over \$400,000 to research and programs in Massachusetts. We are truly grateful to Ron Webb, Tom Yewcic, Kris and Bill Stapelton, Kevin Maguire, and Debbie Case for their dedication. When it comes to golf, the Massachusetts Parkinson's community knows the course inside and out. We applaud the Bogliani Golf Tournament and the McMahon Golf Tournament for their support and welcome the DOPA Golf Tournament to the table after a successful first year.

I am proud to recognize individuals who have taken time and effort to organize fundraisers and so generously donate the proceeds to the APDA Massachusetts Chapter. Meg McAuliffe's Annual South Boston Pub Crawl has become a favorite amongst friends and family. It continues to grow every year as this past year was their 10<sup>th</sup> go-around. James Pereira's band, Liquid Fix planned a benefit reunion show at The Beach House, and the band, friends, and family chose to support the Chapter. During the holiday season, Lillian Olsen organized the third Food Auction at her office. Neither sleet nor snow prevented Lil and her coworkers from enjoying treats and generosity.

Every year I am impressed with the creativity of our volunteers. On behalf of the Executive Board, we are truly grateful for all of you who have donated time and

effort. Without your support, we would not be able to serve the Parkinson's community in the ways that we do.

We have started the 2009 year on the "right foot." In January we had a very successful Parkinson's Walk Kick-off Meeting and there was much excitement. There is a great deal of work to be done for us to

reach our fundraising goal of \$100,000 at this year's Walk-A-Thon. Please mark your calendars for Sunday, June 7<sup>th</sup>. We hope to have another beautiful day with many individuals and teams participating to raise money for research.

As we recognize April as Parkinson's Disease Awareness Month, you may want to check the Calendar of Events on our website for special speakers that will present at different support groups. It is my hope that we will visit the Massachusetts State House to increase awareness.

Our Golf Tournament Committee is wasting no time as plans are under way to tee off on August 28, 2009 at the Sandy Burr Country Club. We are always seeking new golfers and foursomes. Do you know anyone that would like to play golf and help support our Chapter?

Over the past years, I have enjoyed meeting each of you at our many events. Together, I know we will have another successful year!

*Our Annual APDA Chapter Meeting will be held Saturday, April 18, 2009. All Chapter members are invited to attend. Elections will be held, and members will receive updated information from our Chapter Officers.*



*Keith congratulates Gladys Tiedemann, CT APDA Chapter President as she is recognized in Sturbridge for her years of service to the New England Parkinson community.*

## Research Opportunities

### *Coenzyme Q10 Research Study for Parkinson's Disease Patients*

There is a clinical study of the research medication Coenzyme Q10 (CoQ10) in persons 30 years of age or older who have early stage Parkinson's disease. The purpose of this research study is to find out whether CoQ10 can slow the progression of early Parkinson's Disease. Those diagnosed with Parkinson's disease within the last 5 years and are not yet receiving treatment for their symptoms may be eligible. Study doctors will follow participants every four months over a 16-month period. There is no cost to participate in the study. Persons with early stage Parkinson's disease who are interested in participating in this study should contact the Boston University Parkinson's Disease and Movement Disorder Center at 617-638-7737. - IRB H-27250

### *Participants needed for study on the health of caregivers to relatives with Parkinson's Disease*

If you are providing care for a relative with Parkinson's Disease, and you are 60 years or older, you may be eligible to participate in a study on how caregiving affects your health. This study will involve 4 yearly face-to-face interviews, conducted by trained interviewers at the General Clinical Research Center at BUMC in Boston's South End. You will be asked questions about your physical and emotional health, and about the person for whom you provide care. In addition, you will be asked to give blood and urine samples. This study is funded by the National Institute of Health.

The first interview is expected to take 2 hours. It will take place in the early morning. You will be reimbursed up to \$40 for your time, and your parking costs will be paid. You can bring your care recipient to the interview where someone will stay with him or her during your interview.

If you are interested in participating in this study, please call the study coordinator, Mathilde Sabourin at (617) 638-8032. - IRB H 26127

### *Study Evaluating an Individuals Risk of Developing Parkinson's Disease*

This new study is called Parkinson's Associated Risk Factor Study (PARS)

You may be eligible to join if: You have a first-degree relative (mother, father, sibling, or child) diagnosed with Parkinson disease, Your age is 50 years or older, You have not been diagnosed with Parkinson disease yourself, You have no history of nasal trauma or surgery involving your nose or sinuses. If you are interested in participating, please contact us 617-638-7737. For information contact the BUMC Parkinsons Disease and Movement Disorder Center at 617- 638-7745 - IRB # H-26493.



**For additional information on  
ongoing research trials in  
Massachusetts visit [www.pdtrials.org](http://www.pdtrials.org)**

# Autonomic Dysfunction in Parkinson's Disease

Anna DePold Hohler, MD

*Assistant Professor of Neurology, Boston University Medical Center*

Parkinson's disease (PD) is defined clinically as the presence of several of the cardinal motor functions (rest tremor, slowness of movement (bradykinesia), stiffness (rigidity), and walking/balance difficulties) in the presence of a response to PD medications. In addition to the motor features of PD there are numerous non-motor features which include sleep difficulties, mood difficulties, and autonomic nervous system problems to name a few. The autonomic difficulties can include drops in blood pressure (BP) when standing, constipation, urinary frequency, and changes in sweating.

Drops in BP when standing, or orthostatic hypotension (OH), is defined as a drop of 20 points or more in systolic blood pressure (top number in a blood pressure reading) when moving from sitting to standing position. One study found that 58.2% of PD patients have OH. Thirty-nine percent of patients may notice this as a feeling of lightheadedness, leg weakness, a dull headache, or slowed thinking. The highest rates of OH were associated with more severe PD and higher PD medication dosage. Parkinson's disease itself can cause OH and the medications used to treat it may also lower BP. Carbidopa/levodopa, the dopamine agonists, and amantadine can all lower BP. While OH increases with disease severity, it has been shown to precede some cases of PD motor development. Drops in



BP can have negative consequences. They can contribute to fainting spells and falls. One study also linked

sion to more impaired attention and memory. OH is more likely to occur in the morning when a person first gets out of bed. Blood pressure increases naturally over the course of the day.



If you are concerned that your blood pressure may be dropping, there are things that you can do. First, get baseline BP readings sitting and standing in the AM for 5 days. Write down the numbers and note the position you were in, the exact time of day, and if you had symptoms. If there is more than a 20 point drop in the systolic blood pressure (top number) or more than a 10 point drop in the diastolic blood pressure (bottom number), notify your physician. Conservative treatments for OH include increasing hydration with water and electrolyte solutions, compression stockings, abdominal binders, and increasing salt in the diet (if not medically contraindicated). More significant measures include reducing or eliminating anti-hypertension medications, decreasing PD medications, and/or starting medications to increase blood pressure. All treatment strategies must be done under the supervision of your healthcare provider. In some cases, your physician may recommend autonomic testing which involves blood pressure and heart monitoring during different situations to identify OH. Several local facilities offer this testing including The Autonomic Center at Boston University Medical Center.

1. Senaid JM, Rai S, Lapeyre-Maest Metae. Prevalence of orthostatic hypotension in Parkinson's disease. *Journal of Neurology, Neurosurgery, & Psychiatry* (1997) 63:584-589
2. Goldstein DS. Orthostatic hypotension as an early finding in Parkinson's disease. *Clinical Acton Research* (2006) 16:46-54
3. Allcock LM, Ulliyart K, Kenny RA et al. Frequency of Orthostatic hypotension in a community based cohort of patients with Parkinson's disease. *Journal of Neurology, Neurosurgery, & Psychiatry* (2004) 75:1470-1471



## Calendar of Events - Save the Date

**March 26, 27, & 28, 2009**

**A Parkinson's Disease Seminar for Healthcare Professionals: Evidence Based Concepts and Current Treatment Approaches**

*The Boston University Photonics Center  
8 Saint Mary's Street, Boston, MA 02215*

**Thursday, June 4, 2009  
10 am-12 noon**

**APDA I&R Center and MA Chapter Annual  
Winchester Parkinson Symposium**

*Jenks Senior Center  
109 Skillings Road, Winchester, MA 01890*

**Sunday, June 7, 2009  
12 noon**

**23rd Annual APDA Massachusetts Chapter Parkinson  
Walk-A-Thon**

*Reebok International Headquarters  
1895 J.W. Foster Blvd., Canton, MA 02021*

**Friday, August 28, 2009  
8 am registration/breakfast  
10 am shotgun start**

**14th Annual Putt for Parkinson's Celebrity  
Golf Tournament**  
Auction, Raffle, & Lobster Bake.

*Sandy Burr Country Club  
103 Cochituate Road, Wayland, MA 01778*

**Saturday, September 5, 2009**

**2nd Annual Dopa Golf  
Tournament ,  
benefitting the APDA**  
Contact Tournament Founder:  
Bob Tullis at [ardiejr@comcast.net](mailto:ardiejr@comcast.net)

*Bay Pointe Country Club  
Onset, MA, 02558*



**Wednesday, October  
7, 14, & 21, 2009  
6-8:00pm**

**A Good Start Program**

For individuals recently diagnosed with Parkinson's and their families. Contact the APDA I & R center at 617-638-8466.

*Boston University Sargent College  
635 Commonwealth Ave., Boston, MA 02215*

## Parkinson's Disease Seminar for Healthcare Professionals at Boston University

*March 26-28th, 2009*

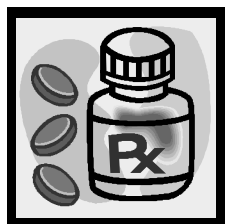


We are pleased to announce the Third Annual Parkinson's Disease Seminar for Healthcare Professionals at Boston University. This unique course continues to provide a cutting-edge, evidenced-based update on the medical and rehabilitative management of patients with Parkinson's disease (PD). Movement disorder experts from Boston University have partnered with the American Parkinson Disease Association (APDA) to bring the latest developments in the field to healthcare professionals invested in providing high quality care to people with PD. For 2009, we have brought back our excellent speakers from last year and invited some additional experts to participate.

Participants will be provided the tools to become resource clinicians in their practice settings in order to optimize the delivery of care to people with PD and their significant others. Registration is required.

For more information, call The Center for Neurorehabilitation at Boston University at 617-353-7525 or visit our website at [www.bu.edu/sargent/pdeducation](http://www.bu.edu/sargent/pdeducation).

## Need help with your prescriptions?



A free and confidential service is now available for Massachusetts residents through the Massachusetts College of Pharmacy & Health Sciences and the Commonwealth of Massachusetts Executive Office of Elder Affairs. By calling a toll-free help line, patients can receive general information about their medications and side effects, in addition to personal assistance with accessing affordable prescription drug programs.

**Call toll-free to MassMedLine: 866-633-1617**

## Become a member of the Massachusetts Chapter of the American Parkinson Disease Association

Fill out the registration form and mail it to  
APDA MA Chapter, 72 East Concord St, C3, Boston, MA 02118

Name \_\_\_\_\_ Date \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Email \_\_\_\_\_ Telephone \_\_\_\_\_

**Membership Fee: \$10 per individual, \$15 per family**  
**Make checks payable to: APDA MA Chapter.**



## 23rd Annual APDA Parkinson Walk-A-Thon! Sunday, June 7, 2009

We are looking forward to this year's Annual APDA Parkinson Walk-A-Thon and we hope you can join us. Last year we raised over \$100,000 and 100% of the proceeds go toward Parkinson's research. *Matty in the Morning* from KISS 108 will be joining us once again for this fun-filled family event. There be chances to win a variety of raffle prizes!

In order to register for the event or find out more information, visit: [apdama.kintera.org/walk09](http://apdama.kintera.org/walk09). Through this informative and user friendly website, team leaders can register teams and participants can either register as an individual or join a team. Each team and individual has the opportunity to create their own page so that they can direct family and friends to join as well as see their progress. Thank you in advance for your support; we look forward to seeing you there!

The Walk-A-Thon will take place on Sunday, June 7, 2009, 12noon, at Reebok International Headquarters located at 1895 J.W. Foster Blvd., Canton, MA, 02021.

[apdama.kintera.org/walk09](http://apdama.kintera.org/walk09)

APDA Information & Referral Center  
at Boston University Medical Center  
72 East Concord St, C3  
Boston, MA 02118

NON-PROFIT ORG  
US Postage  
PAID  
Framingham, MA  
Permit 179