



# The American Parkinson Disease Association

SPRING 2008 NEWSLETTER

A Quarterly Newsletter by The American Parkinson Disease Association, Inc. ©2008

## The American Parkinson Disease Association, Inc. 44 YEARS LATER

The American Parkinson Disease Association (APDA) was officially recognized as a not-for-profit organization by the

State of New York in 1964. APDA is unique in its dual mission of providing information, education and support directly to Parkinson's patients and their caregivers, and also as a major contributor to pioneering Parkinson's disease (PD) research.

Since its inception, APDA has been a funding partner in every scientific breakthrough in understanding the cause and progress towards a cure for PD. Included in that research was the pioneering work of Dr. Roger C. Duvoisin, a chairman of the APDA Scientific Advisory Board (SAB) that pinpointed the location of a gene responsible for PD at Robert Wood Johnson Medical School, New Jersey, in 1997.

APDA's funding methodology is driven by its SAB, composed by 16 of the country's leading physicians and scientists, experts in Parkinson's disease and movement disorder research diagnosis and treatment. Now chaired by G. Frederick Wooten, MD, department of neurology at the University of Virginia Medical Center, the board includes representation from leading research and medical centers across the country including the UCLA Medical School, Emory University School of Medicine, the Mayo Clinic Jacksonville, the University of Wisconsin, the UMDNJ/ Robert Wood Johnson Medical Center, Boston University School of

Medicine, Washington University, Johns Hopkins Medical School, the University of Alabama and the University of Chicago. The board's composition is designed to represent expertise in all areas of PD research providing a knowledgeable panel to evaluate the more than 100 grant applications submitted for funding each year.

APDA support is offered to encourage research at all levels. Nine Centers for Advanced Research across the United States (Boston University School of Medicine, Emory University School of Medicine, UCLA School of Medicine, UMDNJ-Robert Wood Johnson Medical School, the University of Virginia Medical Center, the University of Pittsburgh, the University of Chicago, the University of Alabama, and the Washington University Medical Center) receive a multi-year \$125,000 annual award, and their scientific activity is reviewed and evaluated at the SAB meeting each spring.

The George C. Cotzias, MD Memorial Fellowship, named after a pathfinder in the pharmacological exploration of brain functions and in the treatment of PD with levodopa, is a three-year annual award of \$80,000 to assist promising young neurologists in establishing careers in research, teaching and clinical services relevant to the cause, prevention,

*cont. on page 3*

### INDEX

- 1 The APDA Inc., 44 Years Later
- 2 President's Message
- 4 Q&A
- 5 F.Y.I.
- 9 Senior Living Options
- 10 Weight Loss in Parkinson's Disease
- 11 Sleep and Parkinson's Disease
- 12 Educational Material

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Dear Reader:

In the worst of times/best of times scenario, we are certainly not at either extreme, but at least economically, leaning toward the former. No one is happy about lean economic times, and least of all not-for-profit organizations, which

depend upon the generosity of others.

To make matters worse, in today's not-for-profit area are the stories of abuse in some organizations. While a very small minority, these instances of fraud and downright theft violate the public's trust and make the headlines that taint-by-association the good work done by the many.

Americans gave \$295 billion to philanthropy in 2006, 2.3 percent of the gross national product, and most of those gifts, Bill and Melinda Gates and Warren Buffett notwithstanding, came in small donations. Americans are generous when they can afford to be, but today's Wall Street news and the realities at the supermarket and gas pump are already beginning to affect the amount of disposable income in most families.

Because APDA receives no government or public funding and is dependent upon the generosity of individuals, and to a lesser extent, corporations and foundations, we are particularly sensitive to the moral and economic

phenomena of our times. We wear our Better Business Bureau and other voluntary and regulatory credits as badges of honor.

Regular reports to our contributors and accounting compliance procedures through our board of directors create transparency and a testimony to our integrity. We strive every day to meet our mission to: "Ease the Burden - Find the Cure" for Parkinson's disease.

Now especially, we want all our supporters to know that we are aware of the sacrifice you may be making to continue your generosity. APDA is always appreciative of every gift whatever its form a multi-million dollar estate, a \$10 dollar memorial for a loved one, a charitable gift annuity, or the \$5 bill that recently came to our national headquarters. The slightly yellowed envelope contained a shakily written note: "I know this isn't much, but I want to have a part in finding the cure for this terrible disease."

It is based upon that kind of generosity and hope that we weather the present storm and look forward to the best of times ahead.



Vincent N. Gattullo  
President

## APDA FUNDING SUPPORTS TWO STATES' PD REGISTRIES

Washington has approved a state Parkinson's disease registry. The one-year project initiated last month is being funded by a \$275,000 appropriation and is being administered by the department of health.

The registry is an extension of a voluntary statewide database directed jointly by the University of Washington and the VA Puget Sound Hospital in Seattle, and partly funded by the APDA's state of Washington Chapter.

APDA is committed to the collection of such data, which are vital parts of many scientific research studies. In collaboration with the Michael J. Fox Foundation, APDA is presently supporting the country's first state-supported registry in Nebraska, which after two years and valuable data collected, was suspended because of a shortage of state monies. ■

## APDA GRANT'S FINDINGS PUBLISHED

The March issue of the Physical Therapy Journal reported the results of an APDA-funded research grant. Dr. Leland Dibble, who was awarded a research grant, published his findings with Dr. K. Bo Foreman and physical therapists Jesse Christensen and D. James Ballard titled, "Diagnosis of Fall Risk in Parkinson (sic) Disease: An Analysis of Individual and Collective Clinical Balance Test Interpretation." The study compared the accuracy of PD-fall/risk-diagnosis using one test result rather than an interpretation based on a collection of several tests results ■

## The American Parkinson's Disease Association, Inc., 44 YEARS LATER *cont. from page 1*

diagnosis and treatment of PD and related neurological movement disorders. It is considered APDA's most prestigious individual award.

Established scientists affiliated with research or academic institutions and presently not working on PD research are eligible for the Roger C. Duvoisin, MD Research Grant. The grant carries a two-year, \$80,000 annual award.

Other funding is available as research grants (\$50,000 for one year) for young investigators to pursue research in PD; post-doctoral research fellowships (\$35,000 for one year) available to post-doctoral scientists whose research training holds promise into new insights in pathophysiology, etiology and/or treatment of PD; and medical students summer fellowships designed to provide a stipend to medical students to perform supervised laboratory or clinical research in PD. The fellowship is \$4,000.

At its meeting in May 2007, the SAB recommended more than \$3.5 million in grants, which was unanimously approved by the executive committee of the national board of directors.

Equally important and unique among U.S. PD organizations is the APDA mission to support and educate the country's 1.5 millions with Parkinson's disease and their caregivers. Recognizing the devastating effects of the illness upon the patient and the family, a support program was launched to motivate patients in maximizing their strengths, minimizing impediments and achieving and maintaining their full potential for as long as possible.

Through a network of chapters, which raise awareness and funds; Information & Referral centers, each

staffed with a medical director and a coordinator; and more than 1000 support groups, APDA provides a comprehensive support and educational system for patients and caregivers. There are presently 56 chapters and 62 I&R Centers located in major healthcare and academic facilities across the country, making it the largest grassroots PD organization in the United States.

In 2007, APDA opened the country's first full-time national young onset center to serve the unique challenges of young people faced with the progressive, degenerative disease. The center's director is Julie Sacks, a clinical social worker with more than a decade of experience working with individuals of all ages and their families. The center is located in the Chicago, Illinois area and serves the entire country. Its Web site is [www.youngparkinsons.org](http://www.youngparkinsons.org).

APDA also maintains a dedicated I&R Center for U.S. Armed Forces veterans and their families. Located in Reno, Nevada, the center's mission is to disseminate information about services available to veterans with PD in their home communities and to serve as a resource for information about government benefits available for Parkinson's disease patients.

Education is a primary function of the organization and is provided through a quarterly newsletter, which is mailed to more than 200,000 people internationally. A series of publications includes multi-page booklets written by experts in specific fields such as symptoms and medications, support, physiotherapy, speech problems, and nutrition. Many of these educational materials have been translated into other languages and all are available free of charge. Educational supplements dealing

with specific subjects related to PD are issued as the need may arise.

"Managing Parkinson's - Straight Talk and Honest Hope," is a DVD created for the newly diagnosed patient and his/her loved ones. Leading experts explain what PD is and how it is treated, how to deal with symptoms of the disease, some of the medications' side effects and how to keep a positive outlook in dealing with it.

APDA works collaboratively with other US Parkinson's organizations with similar objectives including the Parkinson's Action Network, a national advocacy association based in the nation's capital, PD Trials, a Web-based service to inform patients of existing clinical trials and to encourage participation and the Michael Fox Foundation to support a PD registry in the state of Nebraska.

Encouraging global cooperation, APDA was the co-sponsor, with the Italian Parkinson Disease Association, of the World Parkinson Disease Association, organized in November 1998. Today, 26 national affiliates from six continents work cooperatively to disseminate the latest information about the progress of PD research, therapy, and all vital information about the disease within their countries. Dr. Paul Maestroni, APDA director of scientific and medical affairs and a WPDA founder, is the president of this association.

APDA is proud of its diverse contributions to the Parkinson's patients of the United States and of foreign countries and the dedication to pursue its mission to "Ease the Burden - Find the Cure" for Parkinson's disease. ■

*This article was compiled from the official history of APDA.*



BY ENRICO FAZZINI, DO, PhD  
Associate Professor Neurology  
New York University, New York  
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**Q:** I have had tremor in my right arm for the last two years. Do Parkinson's disease patients progress at different rates?

**A:** Yes. The older you are at diagnosis the slower the progression. Tremor predominant patients with tremor in their non-dominant side (left arm tremor in a right handed person) have less disability over time than patients with no tremor and only rigidity. Most patients do very well for 10-13 years at which time they lose enough dopamine production to become more sensitive to the medications. At this time they develop troublesome "on/off" fluctuations where the medications work too much or too little with less time they can function normally. Gradually, balance and/or cognitive function become more and more impaired. I have some patients with PD for 20 years who have these "on/off" fluctuations but are still leading near normal productive and enjoyable lives. Note that there are types of PD in which balance impairment is present at the onset, medications do not work, and the disease progresses much more rapidly. These forms of parkinsonism are luckily much less common than regular typical PD.

**Q:** I have had PD for three years. If I take more Requip I get flushed and dizzy. I am also on Azilect. Mirapex did not help. Should I start Sinemet?

**It is getting more difficult to walk and take care of myself.**

**A:** It is my belief that it is duration of disease and not duration of therapy with L-Dopa, which leads to the troublesome side effects of L-Dopa. Nevertheless, Sinemet should be used in low doses and medications like Requip and Azilect maximized.

It seems as if you have increased the Requip and Azilect as much as you can. You should start low dose Sinemet. You can keep the Sinemet dose low by adding Comtan.

**Q:** Neupro is off the market and I did not do well on Mirapex and Requip. I am already on Sinemet 25/250 four times a day and I have periods in which the PD symptoms worsen and other periods when I am jumpy and swaying. What should I do?

**A:** In terms of dopamine agonist therapy, we are in worse shape now than we were in 10 years ago because Permax and now Neupro have been taken off the market. Permax in high doses (over 3 mg/day) leads to an increased risk of heart valve damage. The Neupro patch has been found to be defective – Neupro crystallizes within the patch leading to decreased effectiveness. Dopamine agonists directly stimulate the areas of the brain that need dopamine and their use stabilizes the response to Sinemet. You can add Azilect and

Comtan and reduce the Sinemet to 1/2 tablet every three hours during the waking day.

**Q:** What causes your voice to diminish?

**A:** Hypophonia is a term that describes low voice volume. It is one of the symptoms of PD. You can still speak clearly, but you must make a greater effort to project your voice and use your mouth, tongue and lips better. What was automatic like speech and walking now must be more deliberate. Some patients also slur or stutter their words together. This is called pallilalia and may be a sign of too much medication. You must slow down when this happens. Finally, some PD patients (especially after deep brain stimulation) have a thick, cramped speech. This is dystonia and may respond to medications such as Artane and Klonopin. You should have speech therapy.

**Q:** Can you have Parkinson's Disease and Alzheimer's Disease at the same time?

**A:** You can develop cognitive impairments with PD. This usually shows up as difficulty with concentration and attention. Some patients have severe cognitive impairments at the onset of PD. We call this diffuse Lewy body disease. Medications used to treat Alzheimer's disease such as Exelon or Aricept and even Namenda may help the cognitive impairments associated with PD. ■

## MEET LAURA MARSH, MD SCIENTIFIC ADVISORY BOARD MEMBER

If you casually met Laura Marsh at a party, you would never guess her profession. The vibrant young woman with a quick wit and ready smile might be mistaken for a kindergarten teacher or public relations professional. Few, however, would guess that she is a nationally respected expert on neuropsychiatry and psychiatric disorders related to Parkinson's disease (PD) at Johns Hopkins University School of Medicine.

But if not your stereotypical egghead, Dr. Marsh has always been an academic achiever receiving her BA from Oberlin (Ohio) College with highest honors, and MD cum laude from the Ohio State University College of Medicine, Columbus. Her association with Johns Hopkins Hospital began with a postdoctoral internship in internal medicine and psychiatry residency. Advanced studies took her across the country and to Europe before she returned to Hopkins in 1998. Today, in addition to her academic positions, she is an attending geriatric psychiatrist in the hospital's Department of Psychiatry and Behavioral Sciences and the director of the clinical research program of the Johns Hopkins/NIH Morris K. Udall Parkinson's Disease Research Center.

Dr. Marsh is a prolific author, whose curriculum vitae lists more than 30 pages of publications including articles in scientific journals, editorials, book chapters, abstracts and co-editorship of the book, *Psychiatric Issues in Parkinson's Disease – A Practical Guide*.

Dr. Marsh's interest in psychiatry began in high school when several seemingly ordinary classmates, tragically, committed suicide, and others developed severe mental illnesses. Each case was different but raised the question for her as to what had caused their problems. She began wanting to become a basic scientist studying brain disorders but knew that wasn't her calling when the mice she was studying in a project on alcohol dependence became so aggressive that their brawls caused her nightmares.

A winter term working with schizophrenia researchers in Bellevue Hospital, New York, revealed her love of working with patients. Her focus on neuropsychiatry, the study of psychiatric disturbances in patients with neurological disorders, began when she was in England and Sweden on a Thomas J. Watson Fellowship. The National Institutes of Health, major pharmaceutical companies and national organizations have funded her research.



Dr. Laura Marsh and her 7-year old daughter, Dorothy, enjoying the activities at last month's Unity Walk in NYC.

She began using psychiatric disturbances in conditions like PD or epilepsy as models for understanding problems in the general population. She has found her niche as a psychiatrist, working in the area of PD, where motor, cognitive, and psychiatric aspects of disease are linked in every individual and need to be taken into consideration when providing care to patients and their families. Over time, however, given the high rates of psychiatric and cognitive disturbances in PD patients, one of her goals has been to improve the recognition and treatment of psychiatric conditions by non-psychiatric clinicians to diagnose and treat their patients for psychiatric disturbances, especially depression.

"In particular, we need to do a better job identifying earlier, and throughout the course of PD, who has psychiatric and cognitive problems. It is important that we diagnose patients as soon as they show signs of a mood disorder, because treating depression in a PD patient actually reduces unwarranted disability," she says. "If we wait until they see a psychiatrist, the problem is probably long overdue for attention."

Her time now centers on a family that includes a husband, 7-year-old and 13-year-old daughters, an almost all-black cat and working full-time. Most of her hobbies, such as playing viola in community orchestras, cooking, sewing, and vegetable gardening percolate in and out as time permits, but she always makes time to sew the necessary Halloween costumes. She also tries to combine some fun work and family activities such as working at the Ask the Doctor booth at the Parkinson's Unity Walk, which provides a good excuse to take the family to New York City for a weekend. ■

F.Y.I. is a guide to the efforts and successes and recognition of the hundreds of volunteers and staff who work daily to help ease the burden and find a cure for millions of persons with Parkinson's disease and their caregivers across the United States.

## TEVA NEUROSCIENCE'S BOOK BENEFITS APDA MISSION



Actress Holly Robinson Peete, left, helping to launch "Proud Hands Personal Victories with Parkinson's/A Show of Hands" last month.

Twenty-eight "creative and inspirational" people living with Parkinson's disease (including APDA's Iowa coordinator, Sam Erwin) are profiled in Teva Neuroscience's new book, "Proud Hands Personal Victories with Parkinson's/A Show of Hands." The book includes a foreword by actress, author and singer Holly Robinson Peete, who with her former NFL player husband, Rodney, created the HollyRod Foundation to support those with PD and their families. It was launched at the Parkinson's Unity Walk in Central Park, April 26. Proceeds will be given directly to APDA to support research, people living with Parkinson's disease, their caregivers, and Parkinson's education.

The book is being sent as a gift to all APDA contributors of \$15 or more. Information is available on the Web site [www.apdaparkinson.org](http://www.apdaparkinson.org). Contributions by check may also be sent to APDA, 135 Parkinson Ave., Staten Island, NY 10305 and should indicate "Proud Hands" on the envelope. ■

## IN MEMORIAM

With a sense of great loss, APDA reports the deaths of three benefactors in recent months.

Texas businessman and member of APDA's board of directors for three years: **Marvin Marks** died Feb. 15, in Dallas. For many years Marvin supported the fundraising projects APDA's Northeast Texas Chapter, which has established a Marvin M. Marks Award to be given annually to an outstanding volunteer.

**Nancy D. Barker**, a registered medical technician and phlebotomist who lived with PD for

*(cont. on page 7)*

## It Takes Two to Tango, But an APDA Grant To Prove Its Benefits for People with PD

Fifteen eminent research scientists and physicians were evaluating funding recommendations for research grants during the 2006 meeting of APDA's Scientific Advisory Board. Titles such as "Evaluation of Cerebrospinal Fluid Alpha-Synuclein as a Biomarker for Synucleinopathies," and "The Mechanism of Redox Regulation of the Parkinsonism Associated Protein DJ-1" were among those considered and then along came R-8, "Can Dance Improve Functional Mobility in Parkinson's Disease?"

The premise? Tango lessons, specifically the Argentine tango, can be a tool to balance and mobility improvement in Parkinson's patients. Truth be told, a scientific eyebrow or two was raised.

While an unusually non-scientific title, R-8, however, made the cut and was funded. Dr. Gammon Earhart, Washington University School of Medicine (St. Louis, Mo.) assistant professor of physical therapy, published the successful results in the *Journal of Neurologic Physical Therapy* and captured the imagination of the consumer health media, including the *New York Times*.

MedicineNet.com led a story: "Not only is the tango a dance of romance and passion, it also helps improve balance and mobility in people with Parkinson's disease." The story went on to explain how a group of 19 Parkinson's patients, about half of whom were randomly assigned to do 20 one-hour tango classes, registered much better results in the Berg Balance Scale measuring



mobility and balance than the other half of the group who had strength and exercise sessions designed for Parkinson's patients.

"Some participants were skeptical at first because they hadn't danced in years or because they thought their disease would interfere," Dr. Earhart reports. But she notes that the moves of the tango, including turning, dynamic balance, movement initiation, moving at different speeds and walking backward, accompanied with the social aspect of dancing rather than tedious exercise, resulted in greatly improved functional mobility for all the participants. Madeleine Hackney, a predoctoral trainee in movement disorders is working with Dr. Earhart.

So, while R-8 didn't have the traditional scientific ring to it, it did prove that you can't judge good research by its grant title. ■

## A Message From the National Young Onset Center

From its inception, APDA has recognized the essential role support programs play in the lives of people living with PD, patients and their families.

Younger people with PD, however, tend to shy away from traditional support groups choosing instead from the explosion of Internet social networking sites. These "virtual" support groups have many advantages including no geographic limitations. While this allows for a larger pool of support, young people who only participate in virtual support systems are missing out on an opportunity to create more personal face-to-face relationships.

APDA's National Young Onset Center recognizes that young people with PD have different primary concerns than people diagnosed later in life, and do not always feel comfortable in traditional support group meetings largely composed of older people. Because of this, we are working to increase the number of APDA-affiliated support groups specifically for the young onset population.

I recently received a call from someone interested in

starting a young support group. She had been diagnosed in her 40's, and never had the kind of local support a young onset group could have provided. A recently retired nurse with both a professional and personal perspective of PD to share, she had decided now was the time for her to establish the first YOPD group in her area. Please, consider following her lead! If you are young, or were diagnosed young, and are looking for a new and meaningful way of giving and receiving support, consider starting a YOPD support group in your area. The National Young Onset Center can help you get started (send you materials, notify people in your area, publicize your meeting time/location), or can refer you to a group near you. For more information, contact us at **1-877-223-3801**.

While support groups usually have a leader, members are often involved in establishing the structure and format, and groups tend to be as diverse as their membership. So whether you are starting one or joining one, a support group can be a powerful and empowering experience and the possibilities for support are endless. ■

### Flower Power for Parkinson's

40% donation to PD research

Help APDA in the fight against Parkinson's disease. Make a visible statement and a 40% donation to Parkinson's research at the same time.

We have chosen the breathtaking red tulips with a small white edge, the traditional symbol of hope for Parkinson's disease. These mid-spring bloomers produce egg-shaped flowers on 20-to-24-inch stems and are appropriate for planting in containers for balconies and patios as well. Packages contain 25 top-size bulbs, and make wonderful gifts.

The best part is that APDA will receive 40 percent of the price (excluding shipping costs) of every package of tulips purchased. So, when planting your beautiful tulip bulbs, you are also planting hope for the cure.

Share this offer with friends and family and help Parkinson's research even more. The price per bag, \$29.95, includes all shipping and handling charges. Orders must be received by September 15, 2007.

How to order:

1. Order online at [www.tulipworld.com/APDA](http://www.tulipworld.com/APDA)
2. Call toll free 1-855-688-9547

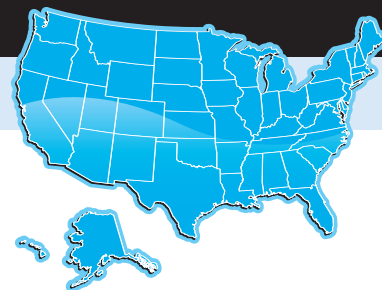
APDA  
TO CARE FOR PARKINSON'S WE BELIEVE IN HOPE

### IN MEMORIAM

(cont. from pg. 6)

more than 27 years, died Jan. 22, in Falmouth, Maine. She and her husband, Carl, dedicated their time and talents as advocates for people with PD from the time of her diagnosis. Carl has served as president of APDA's Maine Chapter, which has established 14 support groups across the state.

**Ronald M. Dillon** died at Georgia War Veterans Nursing Home, Augusta, Oct. 17, 2007 after a 30-year courageous battle with PD. A Korean War veteran, he was the Georgia Chapter president for six years, introduced the first walk-a-thon on the grounds of Wesley Woods, a senior living community in northern Georgia, and raised many thousands of dollars for PD research and education. ■



IN THE  
NORTHEAST

**New Jersey's** annual spring conference, "Living Well with Parkinson's Disease," attracted more than 200 people on March 29. Eminent physicians from neighboring states (Dr. Michele Tagliati of Mt. Sinai Hospital, N.Y.C. and Dr. Daniel Weintraub of the University of Pennsylvania), were joined for the all-day conference by Leslie Gordon, RN, who shared the secrets of The Humor Project, Inc. and Stacie Mishler, director of the Parkinson Unity Walk.

**Maine** coordinator Lillian Scenna was among those giving testimony to the state legislature in support of LD1975, "An Act to Promote Awareness of Parkinson's Disease," earlier this year. The bill called for increased training for emergency and public safety workers regarding proper assessment and care of persons with PD, especially in crisis situations. Last month the Maine Chapter in partnership with MaineHealth presented the sixth annual Parkinson's Awareness Conference, "Brainpower," in Falmouth.

The **New Hampshire** I&R Center's April 19 seminar "Improving Parkinson Disease Treatment Through Innovation and Research", emphasized the "how" rather than the what in PD research and treatment. Among the topics were: how Innovative surgery is used to relieve PD symptoms; how current laboratory research deepens understanding the causes of PD; and how clinical research helps in evaluating new treatments. The program at Dartmouth-Hitchcock Medical Center in Lebanon included participants in discussions to understand better the decision-making process of patients' choices.

IN THE  
SOUTHEAST

Movement authority John Argue, APDA Scientific Advisory Board chairman, Dr. Frederick Wooten, and Dr. Abu Qutubuddin from the Southeast Parkinson's Disease Research education and Clinical Center (PADRECC) addressed the annual Parkinson's Disease Community Education Days. The annual event sponsored by the Richmond (**Virginia**) Metro APDA Chapter, I&R Center of Charlottesville, and PADRECC attracted more than 250 people.

Paula Houston, APDA's **Louisiana** coordinator, had a different approach to promote PD awareness last

month – the center paid for those with PD to attend the Parkinson's exercise class during April, almost doubling attendance. The rationale is that a "free" month of exercise will whet their appetites and they will continue.

Brenda Allred was blown away figuratively at the turnout for the Jackson, **Mississippi** symposium last month mostly because it was almost blown away literally by an 80-mile a hour tornado the previous day. With no electricity or phones, Brenda and the speakers forged ahead in "winds worse than we had during Katrina," and 120 people arrived for the all-day event.

IN THE  
SOUTHWEST

Tucson I&R coordinator, Dr. Cynthia Holmes, presented "Parkinson's Disease - Update," one course in the University of **Arizona's** Mini Medical School series. The series of five evening lectures presented by the College of Medicine included health issues dealing with organ transplants, prescription drugs, PD, basic research and hand injuries.

IN THE  
WEST

Last month's **Washington** State Chapter's Education Patient Care Program included valuable information on medications and non-motor manifestations and physical therapist's Ann Zylstra's easy-to-remember message by its title alone, "Exercise Can Help, But Only If You Do It!"

IN THE  
MIDWEST

PGA golfer Steve Stricker was so impressed with Greg Kopan's \$5,000 donation to APDA's **Wisconsin** Chapter, that he contributed an additional \$10,000. Greg competed in the Madison Ironman Triathlon in Madison in honor of his brother-in-law, Dale Carlstom. Stricker's gift was a portion of the charitable proceeds from the 2007 Presidents Cup at the Montreal Golf Club, a unique event with no purse or prize money. Players instead choose charitable causes. ■



# SENIOR LIVING OPTIONS

By Annemarie Schwarzkopf  
APDA Georgia Chapter President

*Recently, there has been a proliferation of senior housing communities. Families have many choices when the need for a senior housing facility arises. With so many new options in senior housing, we would like to take the time to review some of these with our readers.*

## Independent Living Communities

Independent communities cater to seniors who are very independent and with few medical problems. Residents live in fully-equipped private apartments. A variety of apartment sizes are available from studios to large two bedrooms. Fine dining services are offered with custom-designed meal packages. Often, residents can choose to pay for a specified number of meals per day. Frequently, there are numerous social outings and events to choose from for entertainment.

*Also Known As:* Retirement Communities; Congregate Care; Retirement Living

*Payment Sources:* Mostly private pay; some government funded through HUD section 202

*Price Range:* \$1000-\$2500 per month

## Assisted Living

Assisted living communities are designed for seniors who are no longer able to live on their own safely, but do not require the high level of care provided in a nursing home. Assistance with medications, activities of daily living, meals and housekeeping are routinely provided. Three meals per day are provided in a central dining room. Residents live in private apartments that frequently have a limited kitchen area. Staff is available 24 hours a day for additional assistance. Most assisted living communities provide licensed nursing services. The hours vary greatly, so be sure to ask when you can visit. Social activities and scheduled transportation are also available in most communities. A special unit for Alzheimer's residents is available in some, but not all of them.

*Also Known As:* Assisted Care Community

*Payment Sources:* Mostly private pay; some accept Medicaid

*Price Range:* \$1800 - \$3500 per month depending on the size of apartment level and level of assistance required; Alzheimer's care ranges from \$2800 - \$3800 for a shared suite

## Nursing Homes

Nursing homes provide around-the-clock skilled nursing care for the elderly who require a high level of medical care and assistance. Twenty-four hour skilled nursing services are available from licensed nurses. Many nursing homes now provide short-term rehabilitative stays for those recovering from an injury, illness or surgery. Long-term care residents generally have high care needs and complex medical conditions that require routine skilled nursing services. Residents typically share a room and are served meals in a central dining area unless they are too ill to participate. Activities are also available. Some facilities have a separate unit for Alzheimer's residents.

*Also Known As:* Convalescent Care; Nursing Center; Long Term Care Facility

*Payment Sources:* Private pay; Medicare; Medicaid

*Price Range:* \$4000 - \$8000 per month

## Residential Care Homes

Residential care homes are private homes that typically serve residents who live together and receive care from live-in caretakers. These homes offer assisted care services for seniors who want a more private, home-like community. Assistance with activities of daily living such as bathing and dressing are typically provided. Amenities and nursing services vary greatly among homes. Ask about their services when you tour.

*Also Known As:* Board and Care Homes; Group Homes; Adult Family Homes

*Payment Sources:* Private pay; Medicaid in some instances

*Price Range:* \$1500 - \$3000 per month depending on the services and level of care provided

(cont. on page 10)

# WEIGHT LOSS IN PARKINSON'S DISEASE

By Anna D. Hohler, MD

Assistant Professor of Neurology, Boston University Medical Center

*While obesity reaches epidemic proportions in the United States, neurologists are concerned that individuals with Parkinson's disease (PD) may be losing too much weight. Two studies published last year confirm an association between PD and progressive weight loss and outline the likely reasons for this effect.*

Parkinson's disease (PD) affects dopamine, norepinephrine, and the cholinergic systems. As a result individuals have a decreased sense of smell, they may have less motivation to eat, and their hunger centers may be less active. Swallowing may also be more difficult. Tremor or dyskinesias may also increase an individual's metabolic rate. Stiffness and slowness may make meals more arduous, and decreased gastric emptying and constipation may contribute to weight-loss problems. In one recent study subjects with PD who were older, had visual hallucination and memory problems, were at highest risk for weight loss.

Another study recommended to monitor the weight in individuals

with PD, by keeping close track and having a log of weights taken at least monthly. This will ensure that weight loss is noted and lifestyle and dietary modifications can be made.

Physical exercise to stimulate appetite and to enable maintenance of muscle tone is important to preventing weight loss. In addition, adequate hydration with 6-8 glasses of water a day is advised. This may also help with decreasing constipation.

Individuals who are fatigued with eating three larger meals a day should have 5-6 smaller meals. Taking PD medications 30-60 minutes prior to meals will ensure optimum absorption and effect in time for meals. Choosing high-calorie foods and supplementing with

shakes or other nutritional supplements may also stabilize or increase weight. If you have swallowing or choking difficulties, a swallow study and speech and swallow therapy may be needed.

PD is best managed with a healthy diet, exercise and close monitoring of medications to optimize quality of life.

A well-balanced diet is imperative to a healthy lifestyle. Guidance about specific nutritional recommendations is available in the APDA *Good Nutrition and Parkinson's Disease* booklet. ■

*This article was originally published in the Fall 2007 newsletter of the Boston APDA I&R Center.*

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## Senior Living Options *cont. from page 9*

### Respite Care

Respite care provides a temporary break for caregivers by allowing a resident to have a short-term stay in a community that can meet their needs. Many assisted living communities and nursing homes have a respite care program. Residents typically stay from a week to a month, depending on their situation. They receive all of the services of the community. Respite stays may also serve as a "get acquainted" period for the senior. Many residents find that they enjoy their stay and decide to move in soon after the short-term visit. Respite programs are available for assisted living and Alzheimer's residents.

*Also Known As:* Short-Term Stay Programs

*Payment Sources:* Private pay; Medicaid in some instances

*Price Range:* \$75 - \$100 per day

### Home Care

Home care allows older people to remain in their own homes while receiving the assistance they need to help them remain independent. Typically, home care involves providing assistance with activities of daily living ADLs or instrumental activities of daily living (IADLs) such as transportation, paying bills, making appointments and simply being there to provide companionship and emotional support. Home care services range from once a week to 24 hours a day depending on the needs of the client.

*Also Known As:* Home Health Care; In-Home Personal Care

*Payment Sources:* Private pay; Medicare/Medicaid via certified home health agencies

*Price Range:* Typically an hourly fee

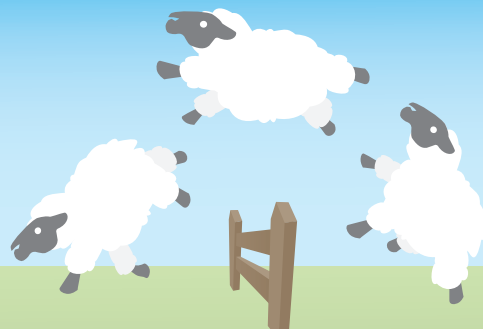
*This article was originally published in the Atlantis APDA Fall 2007 newsletter.*

# SLEEP and PARKINSON'S DISEASE

By Roseanne DeFronzo Dobkin, PhD

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**D**isturbances of sleep are one of the more common problems experienced by people with Parkinson's disease (PD), affecting up to 75 percent of patients. In fact studies suggest that sleep is even more of a problem for patients with PD than it is for the general population or those with other medical conditions who are of similar age.

Typical sleep problems seen in PD include difficulty falling asleep and staying asleep, muscle stiffness and twitches during sleep, vivid dreams, sleep walking, and waking up with morning headaches. Sleep apnea (periods of not breathing during sleep), REM behavior disorder (acting out your dreams in your sleep, often at the risk of injuring yourself or your spouse), excessive daytime sleepiness, and sleep attacks (sudden onset of sleep) are also quite common among people with PD.

The link between PD and sleep difficulties is not clearly understood. It is possible that many of the neurodegenerative changes that occur in PD may directly affect the sleep-wake cycle, leading to sleep disruption. Many of the brain neurotransmitters that help to regulate sleep (like dopamine, norepinephrine, serotonin, and GABA) are also damaged to different degrees in PD. Furthermore, motor difficulties, such as inability to move in bed, dystonic movements and pain from leg cramps may all interfere with sleep.

While dopaminergic replacement therapy may improve sleep in patients experiencing nighttime motor dysfunction, it may also disrupt the normal sleep patterns, as these drugs may be stimulating to some patients. Sleep attacks have also been associated with nearly all available dopaminergic drugs, especially pramipexole (Mirapex) and ropinirole (Requip).

If you are having sleep difficulties, it is very important to discuss your symptoms with your doctor. The first step to appropriate treatment is to ensure proper diagnosis. Doctors may order a formal overnight evaluation in a sleep clinic (sometimes called a sleep study) to identify specific causes of insomnia such as sleep apnea or restless leg syn-

drome. The next step is to treat the specific sleep disorder that is identified. For example, medical conditions such as sleep apnea have specific treatments that have been found to be helpful. Any depression and anxiety should also be identified and treated as these concerns are quite common in PD and nearly always interfere with sleep. Optimization and adjustment of dopaminergic replacement therapy are also critical to successful treatment of sleep disturbance.

The intermittent use of sleep medications may also help patients to fall asleep faster and stay asleep longer. Daily exercise, relaxing before bedtime, keeping regular sleep hours (i.e., going to bed and getting up at the same time everyday), and avoiding excess time in bed, daytime naps, caffeine or alcohol in the evening, and large evening meals may also be helpful. And most importantly, individuals suffering from insomnia should only use their bed for sleep (and sex!) and not for other activities such as paying bills, watching TV, or trying to solve the problems of the day. ■

*This article was originally published in the New Brunswick, NJ APDA I&R Center in Winter 2006-2007.*

## STALEVO IN EARLY PARKINSON'S DISEASE

A new study in patients with early Parkinson's disease demonstrates that Stalevo® (carbidopa, levodopa and entacapone) gives better symptom control and greater improvements in activities of daily living in patients with early Parkinson's disease, than carbidopa/levodopa, the most widely-used current therapy. The results of this study were presented last month at the American Academy of Neurology Annual Meeting in Chicago. ■

*Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling 1-800-223-2732, faxing to 1-718-981-4399, or contacting any of the 62 APDA Information and Referral Centers.*

### BOOKLETS

1. **Basic Information about Parkinson's Disease Brochure** (English)
2. **Parkinson's Disease Handbook** - Symptoms, causes, treatment - booklet (English, German, Italian)
3. **Be Active** - An exercise program for people with Parkinson's disease was recently published by the American Parkinson Disease Association and is ready for distribution. This comprehensive educational booklet was written by Terry Ellis, PT, PhD, NCS, Tami Rork, PT, MSPT and Diane Dalton, PT, DPT, OCS of the Center for Neurorehabilitation, Sargent College, Boston University.

The "Be Active" booklet contains exercises specifically designed for people with Parkinson's disease. In addition, it describes helpful hints to improve day to day mobility. Maintaining an active lifestyle is important for enhancing overall well-being. More and more studies are demonstrating the benefits of exercise for people with PD. The information in this booklet will help people with Parkinson's disease get started on an exercise program and stick with it! The "Be Active" booklet provides the Parkinson's community with the tools they need to get started on a journey towards improving health and wellness.

4. **Be Independent**- Equipment and suggestions for daily living activities - booklet (English)
5. **Speaking Effectively** - Speech and swallowing problems in Parkinson's disease - booklet (English)
6. **Good Nutrition** - booklet (English)
7. **Young Parkinson's Handbook** - booklet (English)
8. **Aquatic Exercise for Parkinson's Disease** - booklet (English)
9. **My Mommy Has PD... But It's Okay!** - booklet for young children. (English)

**The Next Step After Your Diagnosis: Finding Information and Support**-Booklet can be obtained by calling 800-358-9295 and requesting booklet AHRQ Publication No. 05-0049

### SUPPLEMENTS

The Family Unit; The Fine Art of "Recreation & Socialization" with PD; Fatigue in PD; Healthy Aging; Keys for Caregiving; Medications to Be Avoided or Used with Caution in PD; Neuro-Ophthalmology and PD; Medical Management of PD and Medications Approved for Use in the USA and others.

### DVD'S

**Managing Parkinson's** - Straight Talk and Honest Hope.

Created by the Washington State Chapter of APDA for newly diagnosed Parkinson's patients and their loved ones.

A DVD, No AHRQ 07-M025 "Next Step After Your Diagnosis/Tips for Taking Medication Safely" can be obtained, free of charge, from the Agency for Healthcare Research and Quality by calling 800-358-9295, or 888-586-6340 (hearing impaired only) or by e-mailing [www.ahrq.gov](http://www.ahrq.gov)

### APDA WEB SITE

[www.apdaparkinson.org](http://www.apdaparkinson.org) for PD I&R Centers, Chapters, Support Groups, education and information material, meeting dates, publications, medical abstracts, clinical trials and research application guidelines.

### WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

[www.wpda.org](http://www.wpda.org). A weekly updated source of world news.

*Materials concerning research in the field of Parkinson's disease, and answers to readers' questions are solely for the information of the reader and should not be used for treatment purposes, but rather as a source for discussion with the patient's health provider.*