



# AMERICAN PARKINSON DISEASE ASSOCIATION

**FALL  
2012 ISSUE**

**Hello, My Fellow Parkinsonians**  
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**Is There a Connection  
Between Levodopa  
and Melanoma?**

**Failed Drug May  
Be PD Protection**

## FROM LESLIE A. CHAMBERS, PRESIDENT AND CEO

The more folks I meet in the Parkinson's community around the country, the more I hear the word "creative." Whether it is creative caregiving, creative fundraising, or simply creative living, the depth and breadth of ingenuity in so many people's daily lives is inspiring.

Recently I attended APDA's New England Regional conference in Sturbridge, Mass., where the theme of both formal presentations and informal activities was ways to incorporate creativity in dealing with Parkinson's:

- One attendee used his wheelchair for support on the dance floor while he danced to great rock 'n roll music.
- A dance instructor demonstrated the coolest techniques using a soccer ball and a towel to improve gait, stride and balance!
- A volunteer with PD shared how he climbed a mountain with his family and raised money for

research through a simple game of Rock, Paper, Scissors.

- A researcher showed amazing data on the effect of simple exercises on major areas affecting overall quality of life for PD patients...the examples were abundant.

Creativity has served our staff on Staten Island and coordinators in affected areas amid the recent



**APDA President and CEO Leslie A. Chambers, and Old Westbury Information & Referral Center coordinator Eileen Gianetti, second and third from left, share a moment with the Ratner family during the Long Island, N.Y. Dog Walk in Belmont Lake State Park last month. Denise, left, her husband, Dr. Sanford, and son, Aaron, right, are members of the Sonia Rose Team, which Denise formed to honor the memory of her mom, Dr. Sonia Savitzky, who died several years ago from complications of PD. The Ratners, including Cooper and Colby in front, are major APDA Long Island fundraisers.**

help available. Members of our headquarters staff, while tending to their own challenges at home, are volunteering in some of the most devastated areas of Staten Island.

November is National Caregivers Month, and here too, creativity plays a major role in helping people to cope with a progressively difficult, 24-hour-a-day role, while dealing with their own physical and emotional challenges. I invite caregivers to share personal stories, tips and strategies of creative caregiving as they relate to daily living, which we in turn will share with others throughout the country. Mail to my attention or send via e-mail to [lchambers@apdaparkinson.org](mailto:lchambers@apdaparkinson.org) using the word "creativity" as the subject.

And, while there is nothing creative in appreciation, I sincerely thank you for your ongoing support of APDA.

Leslie

events of Hurricane Sandy as well. Despite no electricity, downed live wires, walls of debris and garbage, and interrupted telephone service, APDA has reached out to people with Parkinson's and their families in New Jersey, New York City and Long Island, and made their

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### FALL 2012

Issue No. 100 © 2012

Published quarterly by the American Parkinson Disease Association, Inc.  
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## ASK THE DOCTOR By Erwin B. Montgomery Jr., MD

**Q:** *Is it common for a PD patient to have a sudden onset of depression, anxiety, restlessness, insomnia and thoughts of dying? The patient has been under the care of two doctors for his PD, but he has no relief as yet. His thoughts of dying are getting worse, and I would like to know if there are treatments that can help him now.*

**A:** Depression is a common and often serious concern in patients with PD. Most likely for many patients, the depression is the result of the same kinds of changes in the brain that cause slowness of movement or tremor. In other words, it is not anything the patient has done to cause it or failed to do that could have prevented it. Certainly, the stresses and strains caused by the disabilities of the disease can contribute to or worsen the depression. First, it is important to recognize the presence of depression. Second, it is important to treat the depression aggressively. Not only does depression itself cause disability and place the patient at risk for suicide, it also can make the other symptoms of Parkinson's worse. Often the other symptoms can improve when the depression is treated.



**Dr. Erwin B. Montgomery**

Fortunately, there are many effective treatments for depression including a wide range of medications and psychological treatments. Most often a combination is the most effective. Importantly, psychological treatments may help while the medications take time to work. Many times it may take weeks for the anti-depressant medications to begin to help. In the interim, the psychiatrist and/or psychologist can help monitor the patient from a safety standpoint.

When the situation is severe or life-threatening and urgent intervention is needed or if these traditional therapies fail to be sufficient, electroconvulsive therapy (ECT) can be a lifesaver. There have been many cases where ECT has been very effective and

rapid. Also, there are many reports where ECT can help improve PD symptoms. While not without risk, ECT is reasonable, safe, and very effective; certainly less of a risk than allowing a serious depression with thoughts of death continue. Finally, if there is any concern for suicide, the situation should be handled as an emergency and the patient seen in an emergency room or other urgent care facility.

**Q:** *Are there any data supporting the use of supplements to slow the progress of PD? I have read claims about CoEnzyme Q10, alpha lipoic acid and vitamin C, but don't know if there is any scientific evidence of their validity.*

**A:** There is increasing evidence that patients with PD are impaired in their ability to handle oxidative stress. The cells in the body constantly generate what are called free radicals, which are chemicals that can damage the cells. Normally, the cells have very effective means to get rid of free radicals. However, there is evidence that patients with Parkinson's are impaired in ridding free radicals. In that case, it makes sense that antioxidants such as CoEnzyme Q10, vitamin C, blueberries and other nutrients and supplements would help. However, there is often a big gulf between what makes theoretical sense and what actually helps. That is why it is so important to conduct careful clinical trials, including the use of placebos (like a sugar pill masquerading as the active ingredient). Unfortunately, every clinical study looking at this issue has demonstrated that antioxidants are no better than a placebo.

Consequently, there is no evidence to recommend these agents. The other side of the question is whether it would do any harm to take these agents other than their cost. This is a hard question to answer. First, because many of these nutrients and

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Materials concerning Parkinson's disease research and answers to readers' questions are solely for information and should not be used for treatment purposes, but for discussion with the patient's health care provider.



## FAILED DRUG MAY PROVE EFFECTIVE IN PARKINSON'S DISEASE TREATMENT

Latrepirdine, a drug that had proven effective in treating Alzheimer's disease in Russian Phase II clinical trials only to fail in a Phase III trial in the U.S., is once again showing potential in treating several neurodegenerative conditions including Parkinson's disease. A study by an international team led by Mount Sinai School of Medicine scientists and published in the August 2012 issue of *Molecular Psychiatry*, found that latrepirdine (Dimebon®), reduced the level of at least two neurodegeneration-related proteins in mice.

The lead researcher and director of the Mount Sinai Center for Cognitive Health, Dr. Sam Gandy, MD, PhD, said, "Despite the failure to replicate the positive Russian trial results in the U.S. patients, we found unexpected evidence that latrepirdine had potential

as a treatment for a number of neurodegenerative disorders."

The drug was administered to yeast, mice and mammal cells showing a buildup of alpha-synuclein, a protein known to cause neurodegeneration. In all three models, the drug activated autophagy, the "self-eating" process of cells that protects the brain from neurodegeneration by targeting synuclein and protecting against its toxicity. In the mice model, the drug reduced the amount of synuclein.

Dr. Gandy's team is testing whether latrepirdine might be beneficial in treating or preventing disorders such as PD, Lewy body dementia and REM sleep disorder, associated with high levels of alpha-synuclein.

## WEDDING GIFT IS HOPE FROM BRIDE AND GROOM

Like all weddings, that of Lauren Jacobsen and Jay Colangelo in the Old Church of St. Joachim and St. Anne in Staten Island, N.Y., was a joyful event, but with a twist. Instead of simply receiving gifts, the bride and groom gave them as well – to APDA.

"We have always been community-minded," said the new Mrs. Colangelo, "and we wanted to give back." And they did it in the form of a \$300 check and distributing 190 scrolls telling their guests about APDA and requesting support in honor of her uncle Ronald Martino, who was diagnosed with PD last summer. Uncle Ron is a very special person to me, and he was so touched when I had a special dance with him and the DJ announced that donations to APDA were being given in his honor," Lauren reports.

Lauren heads the Step-by-Step program for children with special needs at the Mission of the Immaculate Virgin, an Archdiocese of New York not-for-profit agency.

## APDA'S 100TH NEWSLETTER ISSUE

For 25 years, APDA has published a quarterly newsletter to share the latest information about research breakthroughs, new therapies, educational programs and resources, and news about its expanding network of chapters, Information & Referral (I&R) centers, and support groups.

In 1987, Ronald Reagan was president and challenged Soviet Premier Gorbachev to tear down the Berlin Wall, the New York Giants won Super Bowl XXI, and the Minnesota Twins won the World Series, the Dow topped 2,000 for the first time, but by October, Black Monday had struck Wall Street.

The newsletter's first article was "Research in Brain Transplantation as a Treatment for PD," Fred Springer was APDA's president, and four chapters and two I&R centers joined the national network. For a quarter century, APDA has been providing this free educational resource for hundreds of thousands of people throughout the world.





## LEVODOPA, MELANOMA AND PARKINSON'S DISEASE: IS THERE A CONNECTION?

By Diane Church, PhD

Levodopa was approved as a treatment for Parkinson's disease in 1968 by the U.S. Food and Drug Administration. In the form of carbidopa-levodopa (Sinemet®), it remains the most common treatment for Parkinson's nearly 45 years later.

In 1972, the case of a PD patient who was treated with levodopa and suffered recurrent malignant melanoma skin cancer was reported. Other cases were subsequently published, and by 1976 it was announced that use of levodopa in Parkinson's patients with melanoma was contraindicated. However, studies had not answered the question: Was the occurrence of melanoma in Parkinson's patients actually caused by levodopa, or was it a coincidence?

At the time, it seemed plausible that there could be an association: Levodopa is the substrate for the synthesis of both dopamine and melanin, which is the substance that accumulates in the darkly pigmented cells of melanoma.

Numerous studies have now shown that people with Parkinson's are at higher risk for melanoma, but that the increased incidence of melanoma is not related to any PD medication. Instead, it appears that melanoma and PD might have shared environmental or genetic risk factors or pathogenic pathways.



Diane Church, PhD

Surprisingly, the Physician's Desk Reference (PDR) still states that carbidopa-levodopa is contraindicated for those with undiagnosed skin lesions or a history of melanoma. It is no wonder that many in the Parkinson's community, as well as numerous medical personnel who do not specialize in PD, still believe that there is a causal link between levodopa and melanoma. Unfortunately, many who would have received relief of their PD symptoms by taking levodopa have avoided this medication for fear of getting melanoma.

### More on Melanoma from the National Institutes of Health:

A mole, sore, lump, or growth on the skin can be a sign of melanoma or other skin cancer. A sore or growth that bleeds, or changes in skin coloring, may also be a sign of skin cancer.

The **ABCDE** system can help you remember possible symptoms of melanoma:

**Asymmetry:** One half of the abnormal area is different from the other half.

**Borders:** The edges of the growth are irregular.

**Color:** Color changes from one area to another, with shades of tan, brown, or black, and sometimes white, red, or blue. A mixture of colors may appear within one sore.

**Diameter:** The spot is usually (but not always) larger than 6 mm in diameter – about the size of a pencil eraser.

**Evolution:** The mole keeps changing appearance.

The key to treating melanoma successfully is recognizing symptoms early. You might not notice a small spot if you don't look carefully. Have yearly body checks by a dermatologist, and examine your skin once a month. Use a hand mirror to check hard-to-see places. Call your doctor if you notice anything unusual.

The NIH also states that the risk of developing melanoma

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## FORMER APDA PRESIDENT SHARES HIS OWN DIAGNOSIS

The man who spent 30 years raising funds to ease the burden and to find a cure for a disease is diagnosed with it one month after his retirement.



**Joel lunched with former Attorney General Janet Reno at the Power of Parkinson Conference in Phoenix in 2006. Back row l-r are then-Arizona Chapter president David Richter, Chapter member Margy McGonagill, and Phoenix coordinator Cynthia Holmes, PhD.**

But that is only one part of the irony of Joel Gerstel's relationship with Parkinson's disease.

Joel, who retired as APDA's president and CEO in August, was diagnosed with Parkinson's syndrome at the North Shore - Long Island (N.Y.) Jewish Health System's Feinstein Institute for Medical Research, where Dr. David Eidelberg is the director. Dr. Eidelberg is a former APDA Dr. George C. Cotzias Fellowship awardee and recipient of APDA's 2005 Fred Springer Award for his contributions to Parkinson's disease research.

Joel had noticed a slight tremor while still working but

dismissed it. His handwriting also deteriorated and he reports it is now very poor. He is taking Sinemet® twice daily and has physical therapy twice a week.

While there is no PD history in Joel's immediate family, there is in his wife Deanne's. It was, in fact, her mother Charlotte Josephs' participation in one of the first clinical trials of the use of the drug dopamine in treating PD at Mt. Sinai Hospital, New York, that peaked her son-in-law's interest in the disease. Ironically, Joel's brother-in-law, Ronald Dillon, a regional salesman for Burlington Industries in Georgia, was also diagnosed with PD and became an active volunteer, serving six years as president of the Georgia Chapter and launching the first chapter walk-a-thon and initiating his then-employer's support, which continues today. Ron died from complications of the disease in 2007. As yet another irony, it was Dr. Ray Watts, a member of APDA's Scientific Advisory Board, current director of the APDA Center for Advanced Research at the University of Alabama – Birmingham, and then at Emory University School of Medicine who diagnosed Ron.

During Joel's administration APDA's revenue tripled, the network of patient and caregiver support grew across the country to become the largest grassroots organization serving Americans with PD, and contributions to research were responsible for many of the most dramatic scientific breakthroughs. Now in his retirement, the fruits of his labor at APDA will be both for him and by him.

## ASK THE DOCTOR continued from page 3

supplements are not regulated by the Food and Drug Administration, the patient has no assurance that what is advertised as being in the supplement or nutrient actually is in the product or what else is in it. Second, there is harm if patients, family members

and/or caregivers use supplements or nutrients instead of tested therapies.

*Dr. Montgomery is the Sigmund Rosen MD Scholar in Neurology at the University of Alabama-Birmingham and a member of APDA's Scientific Advisory Board.*



## SLEEP DISORDERS COMMON IN PD

By Amy Amara, MD, PhD



Dr. Amy Amara

Sleep disorders are very common in patients with Parkinson's disease and can significantly worsen quality of life and daytime functioning. Sleep dysfunction is often present before the motor symptoms (tremor, slowness of movement, stiffness, and balance problems) of Parkinson's disease develop. Different sleep problems that affect PD patients include waking up frequently during the night, daytime sleepiness, leg jerks, and acting out dreams (REM Sleep Behavior Disorder).

REM Sleep Behavior Disorder (RBD) affects up to 15-46 percent of patients with Parkinson's disease and can cause injury to the patient or bed partner. It is important to report these symptoms to your doctor because there are medications that can reduce or stop these behaviors. If you have symptoms of RBD (acting out dreams or fighting or yelling in your sleep), make sure that your bedroom is safe: Remove any weapons from the bedroom; increase the distance between the bed and the bedside table; don't position your bed next to a window; and, if you have fallen out of bed, consider placing your mattress and

box spring directly on the floor.

Patients with Parkinson's disease can also have sleep apnea (stopping breathing during sleep), although it is controversial whether PD contributes to this disorder. Some researchers have suggested that dystonia (abnormal contraction of muscles) of the airway or dyskinesias (excessive movements) may contribute to sleep apnea, but other studies have shown no increased risk of sleep apnea in Parkinson's patients compared to the general population. Regardless, untreated obstructive sleep apnea can cause significant problems, including poor nighttime sleep; daytime sleepiness; increased risk for other medical problems, including heart attack, stroke, heart failure, high blood pressure, depression, anxiety, or memory problems; and worsening of Parkinson's symptoms. The only way to know for certain if a patient has sleep apnea is to perform a sleep study. This is also the best way for a patient to get treatment for sleep apnea. A neurologist or primary care physician can make a referral to a sleep doctor for evaluation.

*Dr. Amara is an assistant professor of neurology at the University of Alabama - Birmingham, and has fellowship training in Movement Disorders and Sleep Medicine.*

## LEVODOPA, MELANOMA AND PARKINSON'S DISEASE: IS THERE A CONNECTION?

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increases with age, and that you are more likely to develop melanoma if you:

- Have fair skin, blue or green eyes, or red or blond hair
- Live in sunny climates or at high altitudes
- Spent a lot of time in high levels of strong sunlight, because of a job or other activities, or use tanning devices
- Have close relatives with a history of melanoma;

### **Some Take-Home Messages**

- Levodopa treatment is not associated with an

increase in diagnosis of melanoma or other cancers.

- People with Parkinson's have an estimated two-to-six-fold increased risk of melanoma but a reduced risk of most other types of cancer.
- Malignant melanoma is a curable disease if treated early. If left untreated, it is potentially fatal.

*Dr. Church is the coordinator of APDA's Information & Referral Center at Dartmouth-Hitchcock Medical Center, Lebanon, N.H. She was an instructor and research associate at Dartmouth College before joining APDA.*

# EDUCATIONAL MATERIAL AND PATIENT SUPPORT RESOURCES

## Information on Parkinson's Disease

APDA is the source of many free educational and patient/caregiver support materials. Most publications listed can be downloaded from the website, [www.apdaparkinson.org](http://www.apdaparkinson.org), publications page. Single copies are available by writing to the national office or calling 800-223-2732, faxing to 718-981-4399, or contacting any of the APDA I&R Centers.

Free subscription to a monthly e-newsletter and "Tip of the Month" feature are available on APDA's website home page. Lotsa Helping Hands, a private, caregiving coordination service that allows family, friends, neighbors and colleagues to create an online community to assist a caregiver with daily tasks can be reached by clicking the "Ease the Burden" button.

**APDA's National Young Onset Center** is located at Central DuPage Hospital, 25 North Winfield Rd., Winfield, Ill. and can be contacted at [www.youngparkinsons.org](http://www.youngparkinsons.org), 877-223-3801, or [apda@youngparkinsons.org](mailto:apda@youngparkinsons.org).

**APDA's National Resource Center for Rehabilitation** provides direct telephone (888-606-1688) and email ([rehab@bu.edu](mailto:rehab@bu.edu)) access to a licensed physical therapist at Boston University's Sargent College, for questions about exercise, information about programs in the caller's area and educational materials.

**APDA's National Veterans Information & Referral Center** is a centralized resource dedicated to supporting and improving the lives of veterans with Parkinson's disease and can be contacted at 888-838-6256, ext. 1715, or [www.reno.va.gov/parkinsons/parkinsons.asp](http://www.reno.va.gov/parkinsons/parkinsons.asp).



### BOOKLETS

(order by letter)

- A.** Parkinson's Disease Handbook
- B.** Young Parkinson's Handbook
- C.** Be Active
- D.** Speaking Effectively
- E.** Good Nutrition
- F.** Aquatic Exercise for Parkinson's Disease
- G.** My Mommy Has PD...But It's Okay!

### SUPPLEMENTS

(order by number)

- 4.** Keys to Caregiving
- 5.** Hospitalization of a Parkinson's Patient
- 6.** The Living Will and Durable Power of Attorney for Health Care
- 7.** Parkinson's Disease and Oral Health
- 8.** The Family Unit and Parkinson's
- 9.** Maintaining Independence

- 10.** The Challenge of Parkinson's Disease: Adapting to a Nursing Home
- 13.** Medical Management of Parkinson's Disease and Medications Approved for Use in the USA
- 16.** When Should Parkinson's Disease Patients Go to the Emergency Room?
- 17.** Neuro-ophthalmology and PD
- 20.** Fatigue in Parkinson's
- 22.** Depression and Parkinson's
- 23.** Incontinence and Parkinson's
- 24.** Employment and Parkinson's
- 25.** Constipation and Parkinson's
- 26.** What is Dysphagia?
- 27.** Cognitive Changes in PD

### OTHER PUBLICATIONS

- Basic Information about Parkinson's Disease
- National Young Onset Center

- How to Start a Support Group
- Medications to Be Avoided or Used with Caution in PD
- 34 Helpful Hints to Improve the Quality of Life of People with Parkinson's
- The Importance of Having a Will

### DVD

- Managing Parkinson's: Straight Talk and Honest Hope, Second Edition

AVAILABLE BY  
DOWNLOAD ONLY  
at [www.apdaparkinson.org](http://www.apdaparkinson.org)

- Be Independent: Equipment and Suggestions for Daily Living
- Dr. Andrew Weil's Recommendations for Healthy Aging