

American Parkinson Disease Association

AMERICAN PARKINSON DISEASE ASSOCIATION

FALL 2011

SHOULD I SEE A NEUROLOGIST OR MOVEMENT DISORDERS SPECIALIST?

By M. Maral Mouradian, MD

What is the difference between a neurologist and movement disorders specialist, and whom should I see for my Parkinson's disease (PD)? These questions are often asked by patients and family members, and the decision as to whose opinion to seek can have a significant impact on patients' care.

Neurologists are physicians trained to diagnose and treat a large number of diseases that affect the brain, spinal cord, peripheral nerves and muscles. During their training as general neurologists, they spend a good portion of their time seeing patients with

APDA CONTINUES ITS 22-YEAR COMMITMENT TO U.S. VETERANS AND THEIR FAMILIES

APDA's commitment to U.S. veterans dates back to 1989 when, with the Sierra Nevada Healthcare System, it opened the first (and remains the only) civilian resource dedicated to improving the lives of America's active and retired servicemen and women with Parkinson's disease. During those 22 years, the center has served more than 6,000 veterans and their families.

APDA's Information & Referral Center at the Department of Veterans Affairs Medical Center in Reno, Nev. provides information, educational resources and referrals to veterans, their families, physicians, nurses and allied health professionals

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APDA FOUNDER SOPHIA MAESTRONE DIES

APDA founder and board member, Sophia Esposito Maestroni, died Sept. 24 on Staten Island, where she had spearheaded the country's largest grassroots organization for Americans with Parkinson's disease by creating its first chapter in honor of her parents half a century earlier. With the love of her family and support of her husband, the late Dr. Gianpaolo (Paul) Maestroni, who served as APDA's director of scientific and medical affairs for 20 years, she provided vision, wisdom, and quiet strength to APDA throughout her lifetime. Surviving are her son, two daughters, seven grandchildren, and three great-grandchildren.



A week before her passing, Mrs. Maestroni celebrated APDA's 50th Anniversary at a gala on Staten Island. With her are (l-r) Sally Ann Esposito-Browne, gala chairwoman and board treasurer; Joel Gerstel, president; Joel A. Miele Sr., board chairman; and Mario Esposito Jr., gala chairman and board member.

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FROM THE CHAIRMAN



Joel A. Miele Sr., PE

The numbers aren't precise, of course, but even by a margin of several hundred thousand one way or the other, there is a near perfect inversion of dollars funded on disaster, tragedies, and diseases to the number of people affected.

In his 2010 best seller, "The Upside of Irrationality," Duke University professor Dan Ariely provides the following giving history for world disaster and disease in comparison to the number of people affected:

Disaster/Disease	Number Affected	Funding (in millions)
Katrina	1.5 million	\$3,200
Asian Tsunami	4.5 million	\$1,600
Tuberculosis	14 million	\$1,200
Malaria	240 million	\$ 700

Half the world's population suffers from malaria, a disease that can easily be controlled, and yet the least amount is given for that.

As Dr. Ariely suggests, there is little rational explanation for why people give, and that applies to time and talent as well as money.

At APDA our appeal is mission-based and performance-driven, not emotional or promotional. Our national team of scientists, healthcare professionals and volunteers continues our dogged work in the laboratory, at the Information & Referral Center, at the walk-a-thon, in the chapter meeting, and at the awareness event – doing our part to "Ease the Burden – Find the Cure."

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FROM THE PRESIDENT & CEO



Joel Gerstel

"Help me now!"

That was the message I heard at a recent meeting of support group leaders.

"I know finding the cure for PD is the ultimate goal, but right now I need help with medications, with information, with services that can keep me going until then."

APDA's national network of 56 Information & Referral Centers is uniquely addressing that plea every day. Across our country, thousands of people with Parkinson's, their caregivers and families look to APDA for guidance in finding help within their communities, and they are not disappointed. We coordinate and assist in maintaining 1,000 support groups from Maine to California and Florida to the state of Washington, making us the largest grassroots organization serving the country's Parkinson's community.

It is a hands-on, labor-intensive – not to mention expensive – mission, and one that does not attract financial contributions as readily as research. There is no dramatic discovery or impressive publication announcing that 25 people in Iowa can now attend an exercise class for free, or that 200 New Jersey Parkinsonians just learned of a service that can help with their medication costs. Illinois and Texas caregivers who benefit from an APDA respite program and Washingtonians who have access to free car service to make doctors' appointments don't get big press.

This is what APDA is about in addition to funding nine of the country's most prestigious research laboratories and providing opportunities for young physicians to work in a PD lab for a summer with the intent of interesting them in pursuing a career in research.

Yes, we are pursuing the cure, but we are also answering the plea, "Help me now!"

ASK THE DOCTOR

By Dr. David G. Standaert, MD, PhD, and Jeri Williams, MD

Q: What is vascular Parkinson's disease (PD) and how does it differ from general Parkinson disease?

A: "Vascular Parkinson's" is really a "parkinsonism," meaning it has some features which are similar to PD but a different cause. Vascular parkinsonism is caused by accumulation of many small strokes (sometimes called mini-strokes). Each of these may be small enough that the symptoms are not noticed when they occur, but over time they build up and the effects become apparent. The most striking feature of vascular parkinsonism is usually bilateral and symmetrical involvement of the lower extremities which causes markedly difficulty walking. The upper body may become affected, but usually this is milder and seen during the late stages of the disease. In most cases, there is little or no tremor. In addition, cognitive impairment, and dementia are more commonly present in vascular parkinsonism when compared with patients who have PD. Unfortunately, vascular parkinsonism does not usually respond very well to therapy with levodopa or other drugs which are effective in PD. The most helpful treatments for vascular parkinsonism are physical therapy and stroke prevention – control of blood pressure, cholesterol, and smoking cessation.

Q: How does Parkinson's affect breathing, or does it?

A: Yes, PD can affect breathing. In Parkinson's disease, there is increased rigidity and decreased elasticity of the respiratory and laryngeal muscles. In addition, the posture may become more stooped which contributes to increasing the work of breathing, as well. Patients who experience dyskinesia from levodopa may also experience chest tightness or irregular patterns of breathing. While the breathing problems from Parkinson's alone are rarely severe enough to be dangerous, when combined



Dr. David Standaert



Dr. Jeri Williams

with underlying lung disease, respiratory infections, or swallowing problems, they can quickly become serious; pneumonia remains the most common cause of death in patients with Parkinson's disease. Prevention is the best weapon; seek medical help for any shortness of breath, persistent fevers, productive cough, or difficulty swallowing.

Q: My husband is 89 and was diagnosed in '02. He seems to require so much sleep and needs to be wakened in the morning after 12-13 hours. He also takes a short afternoon nap. Is this worrisome?

A: As PD progresses, daytime sleepiness and sleep disorders become more common. Some increase in nighttime sleep and mild daytime fatigue are not unexpected. Many patients find a short nap is very recharging, but this should be limited to no more than one 30-minute nap most days, to avoid disrupting nighttime sleep. In those who develop excessive daytime fatigue and a marked increase in the need for sleep the main causes are 1) poor sleep at night and 2) side effects of Parkinson medications. Poor nighttime sleep can be caused by wearing off of PD medications. It can also result from sleep apnea, a serious sleep disorder affecting breathing patterns during sleep. Sleep apnea can lead to low blood oxygen and can

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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.

RECOGNIZING FEELINGS WORKS BOTH WAYS IN PD

Hypomimia, the mask-like face caused by a reduced degree of facial expression that makes it difficult to recognize emotion or feelings, is a known Parkinson's disease (PD) symptom. A recent Harvard Medical School study published in the journal *Neuropsychology*, however, reveals that PD patients themselves have difficulty recognizing other people's feelings.

Heather Gray, PhD, analyzed 34 studies involving 1,295 patients, and found that in addition to making emotion recognition more difficult, PD affects patients' ability to recognize emotions in other people's faces and voices. The condition, she notes, is exacerbated by deep brain stimulation surgery.

The study recommends using other forms of communication with PD patients. For instance, tell the person, "I'm not feeling too happy right now," rather than relying on a frown or sigh to make a point.



Celebrating APDA's 50th Anniversary

Among those celebrating APDA's golden anniversary gala on Sept. 19 were (l-r) Massachusetts I&R coordinator, Cathi Thomas, RN; Scientific Advisory Board member, Mary Maral Mouradian, MD; Connecticut Chapter president, Gladys Tiedermann, and former Connecticut I&R coordinator, Donna Diaz, RN. The year-long celebration honors those with PD and those who work with APDA to "Ease the Burden - Find the Cure."

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common neurological diagnoses including strokes and epilepsy and relatively less time with other less prevalent diseases.

Movement disorders specialists, on the other hand, are neurologists who have done additional training to handle patients with movement disorders. These include PD, benign essential tremor, dystonias, choreas, psychogenic movement disorders, etc. Because of their focus on these problems during their "fellowship" training, these specialized neurologists are proficient in diagnosing and treating patients with these disorders.

The advantages of consulting a movement disorders specialist for PD are many. To begin with,

the diagnosis may sometimes be questionable especially at the early stages of the disease. Some conditions that may look like PD can be other diseases that tend to have a different course than PD and may not respond as well to anti-Parkinson medications.

Second, the treatment of patients with PD can become complicated over time and, therefore, the choice of drugs and fine-tuning their doses and schedule can be critical to providing the most benefit with the least side effects.

Third, PD patients may develop "non-motor" symptoms that affect their quality of life including gastrointestinal complaints, impaired swallowing, pain, sleep

disturbances, memory problems, depression, anxiety and other psychiatric manifestations. Some of these problems may be overlooked and, therefore, go untreated or poorly managed if the physician is not cognizant of their relevance to PD and fails to ask the patient about them specifically.

Fourth, with advancing PD, specialized treatments may be recommended including deep brain stimulation surgery or botulinum toxin injections for special circumstances. A movement disorders specialist is trained to provide such treatments.

Fifth, movement disorders specialists are often trained to conduct clinical trials of new experimental

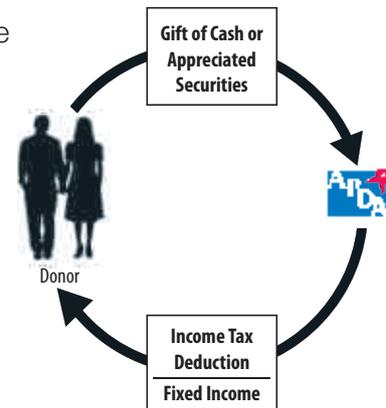
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BE AN APDA PARTNER

There are numerous ways of partnering with APDA to help it meet its dual mission of funding research and providing education and support to patients and their families:

- Give a direct gift by mail, telephone or on APDA's website www.apdaparkinson.org. Donations can be made in memory or in honor of a person or in celebration of or in lieu of gifts on a special occasion, especially upcoming holidays.
- An APDA gift annuity assures a legacy plus a guaranteed income for life. A charitable gift annuity guarantees retirement income until the death of the donor and a spouse, provides an immediate tax deduction, and leaves a legacy to an important personal cause. Call 800-223-2732 to learn of different annuity options.
- Deferred giving in the form of including APDA in your will or making APDA the beneficiary of a life insurance policy. An unrestricted bequest allows APDA to direct your gift to the area it is most needed – patient/caregiver support, research, education. Call to request our publication, "The Importance of Having a Will."

Charitable Gift Annuity



NINDS TERMINATES CoQ10 TRIAL



The National Institute for Neurological Disease and Stroke (NINDS) has stopped the QE3 Phase III of Coenzyme Q10 for treatment of early Parkinson's disease. The study was designed to determine if fairly high doses (1200mg/d or 2400mg/d) of the drug were effective in slowing the progression or served as a neuroprotective for the disease.

NINDS terminated the trial when its Data Safety Monitoring Board concluded that a preplanned interim analysis showed it would be very unlikely to demonstrate a statistically significant benefit of active treatment compared to a placebo.

The study was administered by the Parkinson Study Group and included 600 patients with early PD throughout North America.

ASK THE DOCTOR

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trigger heart disease and stroke. Some of the medications used for Parkinson disease can induce daytime sleepiness. Certain individuals seem very sensitive to this and can develop extreme fatigue even on low doses of medication. In this situation, you should talk with your doctor to decide whether an evaluation for sleep apnea is needed, or whether the medications should be altered to reduce the sleepiness.

Dr. Standaert is a member of APDA's Scientific Advisory Board and the John and Juanelle Strain Professor and Chair of the Department of Neurology at the University of Alabama, Birmingham (UAB). Dr. Williams is the Francis and Ingeborg Heide Schumann Fellow in Parkinson's Disease Research at UAB.



APDA CONTINUES 22-YEAR COMMITMENT TO U.S. VETERANS AND THEIR FAMILIES

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involved in the treatment of PD.

Each Veterans Affairs Medical Center (VAMC) and Community Based Outpatient Clinic (CBOC) is paired with the extensive support group network that APDA has established throughout the U.S., and veterans attend monthly APDA support groups meetings in each state.

“Because veterans often experience a unique set of problems, having a dedicated center for them provides distinct advantages.”

- Susan Gulas, RN

Nevada has nine support groups for veterans and their spouses. One of these groups uses University of Nevada video-television equipment to link patrons who reside more than 200 miles away with support group speakers in Reno. During the last 10 years, veterans and their families have attended nationally recognized educational symposiums, which alternate between Northern Nevada and Southern Nevada yearly.



**Susan Gulas, RN
Veterans I&R Coordinator**

In 2006 the National VA Parkinson's Disease Consortium was established as a means to broaden the impact of the Parkinson's Disease, Research, Education, and Clinical Centers (PADRECCs) and encourage the delivery of modern Parkinson's disease management across the collective VA Healthcare System. Reno is one of 50 U.S. consortium centers. All veterans enrolled in the VA Healthcare System are eligible for

services at a PADRECC or Consortium Center. Additional information on these programs, including directions on how to obtain an appointment, can be found at www.parkinsons.va.gov or by calling 1-800-949-1001 ext. 2749.

John Hollis Peacock, MD, PhD, and Susan Gulas, RN, have respectively served as medical director and coordinator of the center since its opening. Both are involved in PD research at the University of Nevada as well as maintaining an extensive program of information and support at the center.

“We always welcome new veterans and families to local and distant support groups,” says Ms. Gulas. “Because veterans often experience a unique set of problems, having a dedicated center for them provides distinct advantages.”

“Last year,” she reports, “was particularly busy after inclusion of a service-connected disability for PD for Vietnam veterans exposed to Agent Orange.”

The center also maintains a website, www.reno.va.gov/parkinsons/parkinsons.asp, a 24-hour answering service, an extensive lending library of books and audiovisual materials, and publishes a 12-page quarterly newsletter that is distributed to every VAMC and CBOC, and mailed or e-mailed to those who request it. The 2011 edition of the Federal Benefits for Veterans and Dependents booklet is supplied to veterans seeking assistance with health care.

The center can be contacted by calling 888-838-6256 ext. 1715, or e-mailing susan.gulas@va.gov.

For questions about Agent Orange, call VA's Special Issues Helpline at 1-800-749-8387 and press 3. To apply for disability compensation under the new Agent Orange presumptive diagnosis category, visit VA's Agent Orange Fast Track Claims Processing System at <http://www.fast-track.va.gov> or call 1-800-827-1000.

ANTIPSYCHOTIC PRESCRIPTIONS CONTINUE DESPITE FDA WARNINGS

Despite U.S. Food and Drug Administration (FDA) warnings in 2005 and 2008, Parkinson's disease patients in the United States continue to be prescribed, and use, antipsychotic drugs, according to a recent study published in the July issue of Archives of Neurology.

Based upon data from the Department of Veterans Affairs, researchers at the University of Pennsylvania reported that the same number of antipsychotic prescriptions were filled as before the FDA warnings, and that more than half of U.S. patients with PD and psychosis were taking the drugs, despite possible adverse effects and safety risks. Antipsychotics have been shown to worsen symptoms of dementia and psychosis in PD patients.

The researchers concluded that because dementia is a long-term complication for up to 90 percent of PD patients, the associated risks of antipsychotic drug use in PD patients may be higher than previously considered.

The study also notes that a shift toward prescriptions for antipsychotic drugs that are better tolerated by PD patients has taken place, but those drugs are not necessarily more effective or safer.

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medications that are needed to develop better treatments for PD.

And finally, these specialists are typically members of large international medical associations that hold conferences where the latest advances in recognizing clinical problems and newest treatments are presented.

Consulting a general neurologist may be sufficient for mild, uncomplicated PD, but as the disease progresses, special considerations necessitate the expertise of a movement disorders specialist. Often general neurologists recognize this and refer their patients to specialized centers.

The practice of medicine is a science and an art that physicians



acquire with experience, and this is no different in managing PD.

Dr. Mouradian is the William Dow Lovett Professor of Neurology and Director for Center for Neurodegenerative and Neuroimmunologic Diseases, University of Medicine and Dentistry of New Jersey - Robert Wood Johnson Medical School. She is also a member of APDA's Scientific Advisory Board.

FEDERAL GOVERNMENT PROVIDES NEW COVERAGE OPTION FOR UNINSURED

Parkinson's patients often find it difficult to secure health insurance because of their pre-existing condition, but they may now be eligible for a new program created by the Affordable Care Act signed into law in March 2010. The Pre-Existing Condition Insurance Plan is available in all 50 states.

Qualifications include being a U.S. citizen or legal resident, having been uninsured for at least six months before applying, and having a pre-existing condition or having been denied insurance coverage because of a health condition. Like standard health plans, there is a monthly premium, a deductible and some cost-sharing expenses, but premiums will not be higher because of a medical condition and eligibility is not based upon income.

Detailed information on each state's methods is available at www.pcip.gov and clicking on the appropriate state, or by calling 866-717-5826. Monday through Friday, 8 a.m. to 11 p.m. Eastern Time.

Application can be made only by telephone or website, and the Department of Health and Human Services warns against illegitimate calls or letters asking for a fee.

EDUCATIONAL MATERIAL AND PATIENT SUPPORT RESOURCES

APDA is the source of many free educational and patient/caregiver support materials. Most publications listed below can be downloaded from the website, 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 Road, Winfield, ILL. www.youngparkinsons.org, 887-223-3801, info@youngparkinsons.org.

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



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?

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

WEBSITES

- www.apdaparkinson.org
- www.youngparkinsons.org

DVD

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

AVAILABLE for DOWNLOAD at www.apdaparkinson.org

- Be Independent: Equipment and Suggestions for Daily Living
- Dr. Andrew Weil's Recommendations for Healthy Aging (Supplement 21)

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