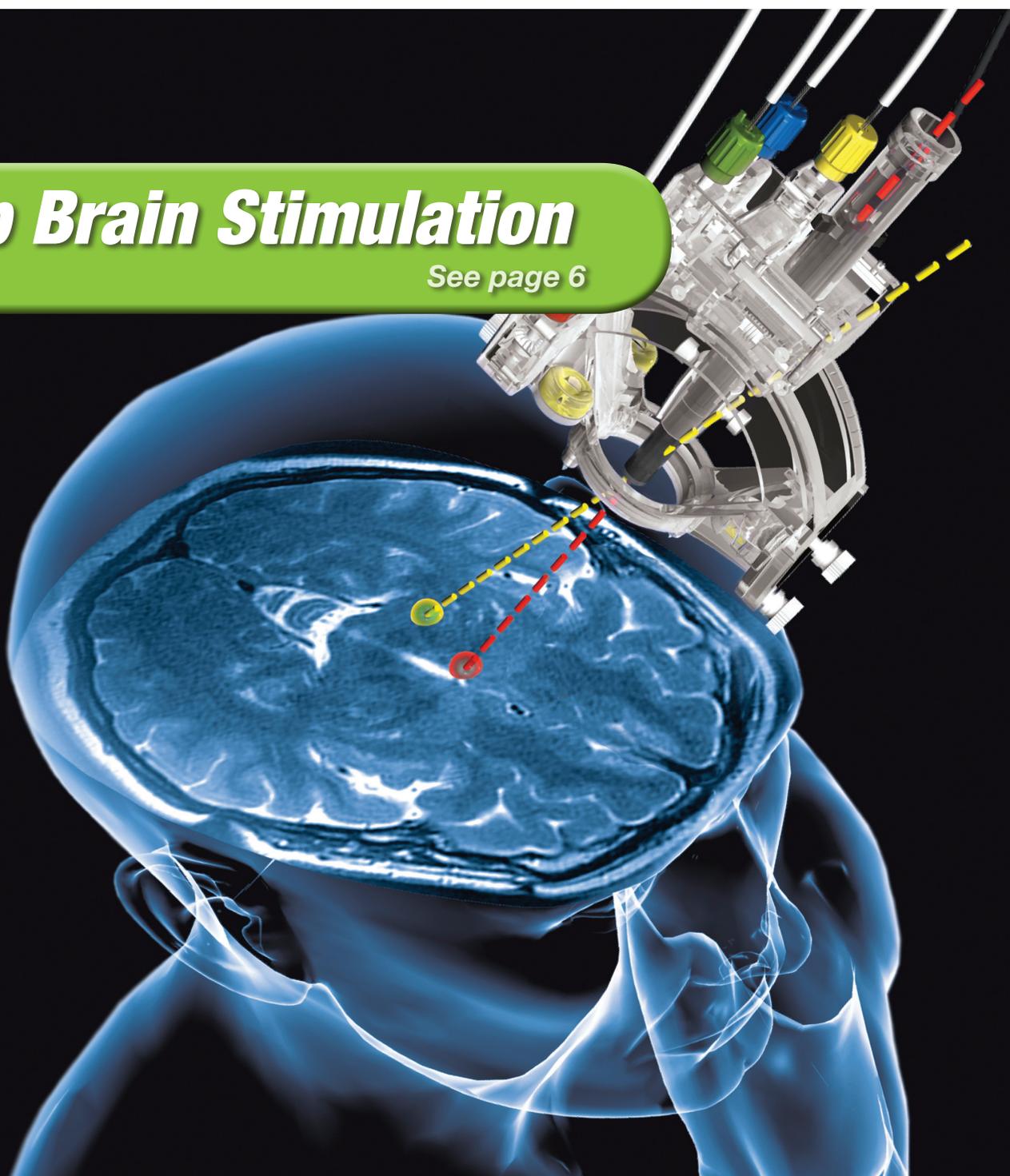


## *Deep Brain Stimulation*

See page 6



- What it is
- Latest technology
- Long-term outcomes research

I take over the chairmanship of the American Parkinson Disease Association — but not without great sadness — from a friend whom I greatly admired and who recently passed away, Joel A. Miele Sr.

As chairman and a longtime volunteer on behalf of Parkinson's patients and caregivers, Joel set a standard in so many ways, seeking to "Ease the Burden - Find the Cure" for Parkinson's disease. As a result of Joel's leadership, APDA has initiated programs and activities to reflect a new direction, acknowledging what I learned years ago: "Change Is The Hallmark of Our Times."

As the nation's largest grassroots organization devoted to the needs of Parkinson's patients and their caregivers, APDA is focusing on ways to strengthen its services further. But we need your help!

We're doing everything we can to expand and broaden our services, but we can only be as successful as the volunteer efforts of our friends, supporters and donors.



*Fred Greene*

As a former caregiver — my wife passed away in 1991 from the effects of Parkinson's — I know how APDA services contributed to improve the quality of life for us.

Join in the APDA effort. Commit time and financial gifts to assure that our mission succeeds and that we truly do ease the burden while we seek a cure.

## In Memory of Joel A. Miele Sr. *Chairman, Board of Directors*



*Joel A. Miele Sr.*

There are people who possess knowledge, experience and leadership quality. Occasionally they are also compassionate and generous. Rarely does one individual have all these qualities plus a magnetic personality and sense of humor. Such a human being was Joel A. Miele Sr., and APDA was fortunate to have him as its champion for 18 years and chairman for five.

Mr. Miele, who was a retired U.S. Navy rear admiral, held three New York City commissionership appointments, and headed a forensic engineering firm, passed away on May 6, after long and valiant battle against cancer.

APDA president Leslie A. Chambers said, "Though I knew and worked with Joel for too short a time, his knowledge, vitality, commitment and dogged determination have left an indelible mark. Even in the last days of his life, he was on the telephone working for APDA and the people who are afflicted with Parkinson's disease. We all miss him."

He is survived by his wife, Josephine, three children, Joel A. Miele, Jr., Vita Marie Chu, Janet Powers and seven grandchildren.

### **SUMMER 2013**

Issue No. 103 © 2013

Published quarterly by the American Parkinson Disease Association, Inc.  
135 Parkinson Ave.  
Staten Island N.Y. 10305  
800-223-2732  
apda@apdaparkinson.org  
www.apdaparkinson.org

### **Chairman of the Board of Directors**

Fred Greene

### **President & CEO**

Leslie A. Chambers

### **Editor**

Kathryn G. Whitford

### **Scientific and Medical Affairs Advisor**

G. Frederic Wooten Jr., MD

### **National Young Onset Center**

Julie Sacks, Director

# ASK THE DOCTOR

By Marie Saint Hilaire, MD



Dr. Marie Saint Hilaire

**Q:** My father has been diagnosed with Parkinson's disease for about two years. He is 79. He has been on Sinemet, Azilect, and Aricept, with no real tweaking of the meds. His disease has progressed rapidly. My sister

and I believe this is due to no exercise program. We want to make sure that physical therapy is designed to help as much as possible. Is there anything I can read or any special resource or special program that can give us guidance?

**A:** Your sister and you are correct regarding physical therapy. Physical therapy (PT) is an integral part of the treatment of PD at every stage of the disease. There is accumulating evidence revealing the benefits of PT and exercise in reducing disability in persons with PD. Studies have shown that PT improves mood and quality of life and that inpatient PT can be beneficial even in advanced disease. It is important, however, that the exercise be tailored to the patient's physical and cognitive abilities. Ideally, the evaluation should be done by a therapist with PD experience. We suggest you contact the APDA National Resource Center for Rehabilitation. Its toll-free helpline (888-606-1677) enables you to speak with a licensed physical therapist who can provide information about programs in your area and educational materials.

**Q:** In the later years of Parkinson's, my brother-in-law, the sweetest, most loving man, suddenly became violent toward my sister. A change in

meds corrected the problem. How common is this side effect?

**A:** Behavioral disturbances are common and varied in PD. They are caused by the disease itself and/or by the effect of PD medications. It is well documented that depression and anxiety are frequently seen in PD and must be treated with counseling and, if necessary, appropriate antidepressant or anxiolytic medication.

Another symptom is apathy without depression, a lack of desire to do anything. It is usually more distressing to the family than to the patient and is difficult to treat.

Medications used for the treatment of PD can cause other problems, such as hallucinations, delusions, and obsessive compulsive behavior. Hallucinations are usually visual, consisting of seeing animals or people who are not real. They can also be auditory. If they are mild, they may not be bothersome to the patient or the family, but they can become frightening and disturbing, especially if the patient has no insight and thinks they are real. Delusions are fixed beliefs that are wrong, such as believing that a spouse is having an affair. The person affected has no insight and can become angry and violent against the spouse.

Consultation with the patient's neurologist and changing medications are needed to control this problem.

Dopaminergic medications, especially dopamine agonists (Ropinirole, Pramipexole, Rotigotine) can cause obsessive compulsive behaviors such as excessive gambling, eating, shopping, watching pornography, and others. These can cause financial, legal, and familial distress and will resolve if the responsible medication is decreased or stopped altogether.

*Dr. Saint Hilaire is Director of the Parkinson's Disease & Movement Disorder Center at Boston University School of Medicine, and member of APDA's Scientific Advisory Board.*

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.

# Young Onset Update

## Speak Up: Tips for Teaching People How to Treat You

If you have Parkinson's disease, chances are you know what it's like being disregarded or disrespected — “dissed” as the younger folks call it. You may have felt dissed when a physician didn't seem to take your concerns seriously or when a friend or family member focused more on your disabilities than abilities. Many younger people with PD are telling us about their experiences like these, but it's not a concern exclusive to young onset.

We all know that Parkinson's disease involves a host of motor and non-motor symptoms. People generally have varying degrees of physical limitations and may have some psychological and/or cognitive limitations as well. However, limitation is not the same as obliteration. Being treated as though you're irrelevant can lead to feelings of depression, helplessness or resignation. It can be tempting to deal with this by withdrawing or isolating yourself from others. Instead, see if you can use one of the following strategies to turn a challenging situation into a meaningful discussion:

### **Tell people how you'd like to be treated.**

- *I'm finding that socializing in small groups is much easier for me than in large parties.*
- *Doctor, I've been having a great deal of anxiety about this symptom and I'd like to discuss it with you one more in time.*

### **Educate others about PD symptoms and treatment.**

- *I'm part of the 50 percent of people who are diagnosed with PD but don't have a tremor.*
- *I've had deep brain stimulation surgery; that's why there's such a difference from the last time you saw me.*

### **Focus on the here and now.**

- *We know this is a progressive illness, but for now I can still...[walk, run, work, play golf].*
- *I know you don't want me to get too tired. I promise to tell you if I've taken on too much.*

Additional suggestions for managing common limitations can be found on our website at <http://www.youngparkinsons.org/resource-guide/employment-disability/disclosure-accommodation>. You may also contact us at [apda@youngparkinsons.org](mailto:apda@youngparkinsons.org) or call us at 877-223-3801.

Many APDA supporters elect to continue their commitment to easing the burden and finding the cure by deferred giving programs. Talk with your attorney about remembering APDA in your estate plans and call 800-223-2732 for our free publications, “The Importance of Having a Will,” and “Charitable Gift Annuities: Guaranteed Payments for Life!”

## Former Regional Representative Barbara Berger Dies in Georgia

Barbara Berger, former Georgia Chapter president and Southwest area regional representative, died June 25 in Snellville, Ga. Barbara knew of PD first-hand as caregiver to her husband, Marvin, a 32-year member of the Chicago Police Department, during his 11-year journey through Parkinson's.

Born in Illinois where she earned her bachelor's degree and RN, Barbara learned she also had talent as an advocate, and after Marvin died in 2003 she dedicated the rest of her life to working for education and support, which she considered crucial in living with the disease.

APDA and the many people who benefited from her selfless giving will miss her.



Barbara Berger

# PD Prevalence Facts: Where the U.S. Stands

The United States, with a rate of 329 per 100,000 ranks third in Parkinson's disease prevalence per 100,000 of populations in countries where it is known. (Albania is the highest with 800 and Egypt second with 557 per 100,000.) It, however, hold the dubious distinction of having the world's second highest prevalence in a specific community, and the highest rate of any region in North America.

The Amish, or Pennsylvania Dutch, a devotedly religious group that lives in almost isolated communities primarily in the Northeast and eschews modern technology including electricity and automobiles, has a rate of 970 per 100,000, second highest in the world only to the rural Egyptians living along the Nile River with a reported 1,013 diagnoses per 100,000. The very high Amish prevalence, which is approximately three times the U.S. average, was first believed to be genetic because the group is disproportionately afflicted by numerous genetic diseases such as cystic fibrosis, muscular dystrophy, deafness and Ellis-van Creveld syndrome (a form of dwarfism). With PD, however, the closer members were

related, the less they were affected. Though not yet researched, current thought is that because the Amish are primarily involved in agriculture, environmental toxins may be a factor.

The heavy use of fertilizer and insecticides in the largely agricultural state of Nebraska is suspected to account for the 329.3 people per 100,000 with reported PD. Nebraska was the first state to create a PD registry in the United States in 1996 and began collecting data from early 1997. In the next seven years researchers measured prevalence in the urban Omaha area and found 3.48 per 100,000 of those age 60 or more versus 14.82 per 100,000 in the agricultural central region. The registry was suspended in 2004 for budgetary reasons and APDA and the Michael J. Fox Foundation for Parkinson's Research committed to co-funding it for three more years, but the state reinstated it in 2006.

Native Americans, both in the continental states and in Alaska, also have higher than average prevalent rates, 355 per 100,000.

Your contribution may be worth twice as much to help "Ease the Burden – Find the Cure." Ask your human resources department if your employer has a matching gift program.



## Flower Power for Parkinson's

Help APDA in the fight against Parkinson's disease. Make a visible statement and a **40 percent 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 20-24 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.

The price per bag, \$29.95, includes all shipping and handling charges. Orders must be received by November 1, 2013.

Two ways to order:

1. Order online at [www.tulipworld.com/APDA](http://www.tulipworld.com/APDA)
2. Call toll free 1-866-688-9547



TulipWorld guarantees the quality of its bulbs and assumes all responsibility for delivery. Packages will be sent in October.



# Deep Brain Stimulation

## What Is DBS?

Deep brain stimulation (DBS), a surgical procedure involving the implantation of a device called a neurostimulator that delivers tiny electrical signals in the areas of the brain that control movement, was approved for use in Parkinson's disease by the Food and Drug Administration in 2002. Though not a cure for PD, it is used for patients whose symptoms can no longer be adequately controlled with medication or have severe medication side effects. It does not stop the disease progression nor eliminate all need for medications, but when successful, DBS significantly improves quality of life.

The system includes a thin, insulated wire or lead placed in the brain; the neurostimulator (similar to a heart pacemaker) usually placed under the skin near the collarbone, and a thin insulated wire or extensions connecting the two. The process is done in two surgeries, the first to place the lead and the second to place the neurostimulator.

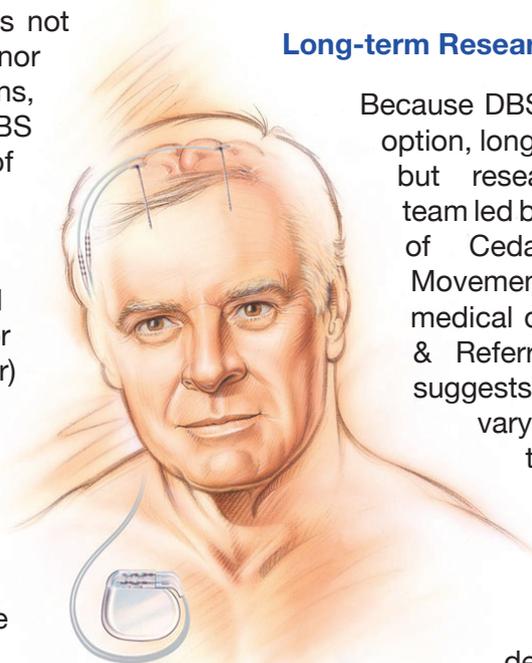


Photo credit: Medtronic

## New Technology

Until recently, it was required that patients be off their medication and awake during the initial surgery to provide feedback for the precise placement of the lead, which frightened some candidates who might have benefited from the procedure. A relatively new process called image-guided intervention surgery, however, provides guidance for the placement of the device utilizing real-time MRI and allows the use of general anesthesia. Surgery is performed with special non-magnetic instruments and the MRI is used to plan the trajectory and, after placement, to confirm that the electrodes are in the appropriate areas. In addition to allowing the patient to be asleep during surgery, the system is magnet-based eliminating the risk of radiation from continuous imaging during surgery, and does not require patients to be off their medication before

surgery. It also allows surgeons to see any brain shift or other movements that may require an adjusted trajectory. According to Dr. Brian Koppel, director of the Mount Sinai Hospital (NYC) Center for Neuromodulation, "What we are seeing is the birth of image-guided surgery allowing the patient to be asleep during the procedure, and a sleeping patient is a happy patient." He predicts that within five years, this will be the standard procedure for movement disorder surgery.

## Long-term Research

Because DBS is a relatively new treatment option, long-term results are not available, but research recently published by a team led by Michele Tagliati, MD, director of Cedars-Sinai Medical Center's Movement Disorders Program and medical director of APDA's Information & Referral Center at Los Angeles, suggests that electrical current may vary over time and deviations from these settings may have the potential to alter patients' outcomes.

"Deep brain stimulation devices are currently designed to deliver constant, steady voltage, and we believe consistency and reliability are critical in providing therapeutic stimulation. But we found that we cannot take impedance stability for granted over the long term," said Dr. Tagliati, the senior author of a journal article that reveals the study's findings.

Cover photo credit: ClearPoint Neuro Intervention System for asleep deep brain stimulation surgery

An APDA charitable gift annuity or deferred gift annuity guarantees income for the life of one or two beneficiaries your legacy to Parkinson's disease research, patient education and support afterward. Call 800-223-2732 for the free publication "Charitable Gift Annuities: Guaranteed Payments for Life!"

# Veterans Update

## Online Personal Video Series Helps Understanding of PD

The Department of Veterans Affairs, Employee Education System and the PADRECC Parkinson's Disease Education & Clinical Center have created a "My Parkinson's Story" Film Library Video Series, an online educational medium to increase awareness within the Parkinson's disease community and non-movement disorders specialists about commonly encountered clinical issues in people living with Parkinson's disease.

The series features 14 short episodes with patients who share their personal experiences about a particular aspect of living with Parkinson's disease. The patients were selected from the National Veteran's Affairs Medical Healthcare system along with their local expert providers to create a library of clinical information using an online webisode format.

Individual webisode subjects are:

1. **The Impact of Depression in Parkinson's Disease**
2. **Overcoming Sleep Problems in Parkinson's Disease**
3. **Impact and Treatment of Falls for Persons with Parkinson's Disease**
4. **Early Parkinson's Disease Symptoms**
5. **Thinking and Memory Problems with Parkinson's Disease**
6. **Deep Brain Stimulation and Parkinson's Disease**
7. **Driving and Parkinson's Disease**
8. **Hospitalization in Parkinson's Disease**
9. **Exercise and Parkinson's Disease**
10. **Advanced Parkinson's Disease**
11. **Impulse Control Disorders**
12. **Medications and Parkinson's Disease**
13. **The Role of the Caregiver**
14. **Speech and Swallowing**



The web Site [http://www.youtube.com/playlist?list=PL3AQJV0BEyxd5tkfQG-S3p\\_SDYBFtJ6c](http://www.youtube.com/playlist?list=PL3AQJV0BEyxd5tkfQG-S3p_SDYBFtJ6c) lists all 14 webisodes.

There are many ways to remember APDA in your will. You can donate a fixed amount or percentage of your estate, specify certain stocks or real estate, or establish a charitable remainder trust to allow your beneficiaries to receive income before a charity benefits from your gift. Call 800-223-2732 for our free publication, "The Importance of Having a Will."

# 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](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 subscriptions to a monthly e-newsletter and "Tip of the Month" feature are available on APDA's website home page. Losta 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 IL; [www.youngparkinsons.org](http://www.youngparkinsons.org), 887-223-3801, [info@youngparkinsons.org](mailto:info@youngparkinsons.org).

APDA's National Resource Center for Rehabilitation provides direct telephone (888-606-1688) and e-mail ([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 Center is located at 975 Kirman Ave., Reno, Nev. 89502; 888.838.6256 ext. 1715, [susan.gulas@va.gov](mailto:susan.gulas@va.gov).



## BOOKLET

(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
13. Medical Management of Parkinson's Disease and Medications Approved for Use in the U.S.A.
16. When Should Parkinson's Disease Patients Go to the Emergency Room?
17. Neuro-Ophthalmology and PD
20. Fatigue and 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
28. Too Little Exercise and Too Much Sitting: A Recipe for Change **New!**

## OTHER PUBLICATIONS

- Basic Information about Parkinson's Disease
- National Young Onset Center
- 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](http://www.apdaparkinson.org)
- [www.youngparkinson.org](http://www.youngparkinson.org)
- [www.reno.va.gov/parkinsons/parkinsons.asp](http://www.reno.va.gov/parkinsons/parkinsons.asp)

## DVD

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

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

- Be Independent: Equipment and Suggestions for Daily Living
- Dr. Andrew Weil's Recommendations for Healthy Aging (Supplement 21)
- The Challenge of Parkinson's Disease: Adapting to a Nursing Home