

# Dopamine Agonists

## *In Parkinson's Disease*

*By Michael Rezak, MD, Ph.D.*

**D**opamine receptor agonists constitute a class of drugs used to treat Parkinson's disease symptoms that mimic the action of naturally occurring dopamine. They stimulate dopamine receptors directly without being metabolized to another compound as levodopa. Although this class of medication is less potent than levodopa, it can be very beneficial in treating symptoms for long periods of time.

The first agonist released was Parlodel® (bromocriptine) in the 1970s. Parlodel firmly established the beneficial role that this class of drugs can play in the treatment of PD. Subsequently Permax® (pergolide), Mirapex® (pramipexole) and Requip® (ropinirole) were released in that order. It should be noted that Permax

has been discontinued because of its ability to cause cardiac complications. Recently, RequipXL® has become available. It has the advantage of being given once a day because of its long half-life. Apokyn® (apomorphine), a powerful injectable dopamine receptor agonist, is indicated for the treatment of acute and

unpredictable episodes of hypomobility, i.e., "off" episodes. Apokyn can be thought of as a "rescue" medication, with onset of action within 10 minutes. Apokyn is the first Parkinson's drug that can be delivered by injection, but patients must be simultaneously taking an antiemetic (anti-nausea) drug because of its strong propensity to induce nausea and vomiting. Neurpro®, a transdermally delivered (via a skin patch) dopamine receptor agonist was available for treating early PD. This drug was unique in that it delivered a steady amount of medication over a 24-hour period. Neurpro has recently been taken off the market in U.S. because of issues surrounding crystallization of the medication onto the surface of the patch.

At least five subtypes of dopamine receptors (D1-D5) have been identified in the brain. It appears that the D1, D2 and D3 receptors are located in the striatum, a major target of dopamine neurons projecting from the substantia nigra. The role of the D3-D5 receptors is not fully known, but they have been suggested to play roles in neuroprotection, psychosis and mood changes. The dopamine receptor agonist drugs differ in their affinities to bind to these different receptors, perhaps accounting for some of their different effects. Mirapex and Requip bind moderately to the D2 receptor and more strongly to the D3 receptors. Interestingly, Apokyn binds strongly to the D4 receptor and has a moderate affinity for the D2, D3 and D5 receptors. Although it is unclear how significant these

*continued on page 3*

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## PRESIDENT'S MESSAGE



*President Miele, right, introduces 2009 Salvatore Esposito, Sr., Award winners at APDA's annual conference in Seattle in July. Maxine Dust, left, and Susan Dietrich, right, were honored as outstanding Chapter president and Information & Referral Center coordinator, respectively.*

### Dear Reader:

I listen to a lot of economic news, and in New York City there is more than enough to satisfy any “business junkie.” What amazes me most is that given the same figures, trends, and forecasts, the “experts” can conclude diametrically opposite outcomes.

#### Whom do you believe?

A New Yorker magazine story last summer told of an execution of a young man convicted of setting a fire that killed his three young children. The conviction was based upon “expert witnesses” in a fire investigation. Their expertise was founded totally on experience and, unfortunately, it was after the fact that a scientist proved that the fire had been accidentally started.

#### Whom do you believe?

It is very difficult in this age of message bombardment by “experts” and constantly changing “facts” to come to the most important conclusions affecting your life.

#### Experience or new technology?

We at APDA embrace technology but temper it with the experience of people – scientists, clinicians, healthcare professionals, patients and caregivers. Our

Scientific Advisory Board, for example, is composed of 15 renowned researchers, some of whom have more than 30 years experience, working with younger experts in areas who bring expertise from emerging specialties. As stem cell research, deep brain stimulation, neuropsychiatry, and physiotherapy became important factors in Parkinson's disease research and treatment, we added experts in those fields to our board.

Through our nationwide network of Chapters & Information & Referral Centers, new programs' successes and failures are shared by Chapter presidents and Center coordinators helping them to make decisions for their own constituents. Tempered with the understanding that what works in Maine may not work in Utah, APDA members function as a team in supporting and assisting each other.

This exceptional amalgamation of technology and human experience is what makes APDA different. And, our unique dual mission reflects our philosophy – put every new concept to the test of human experience and use the result to “Ease the Burden – Find the Cure.”

That has been our guiding principle in the best of times, and that is how we are seeking the truth now.

Sincerely,

A handwritten signature in black ink, appearing to read 'Joel A. Miele, Sr.'.

Joel A. Miele, Sr. PE  
President

### Gianpaolo Maestrone (Paul), DVM

Gianpaolo Maestrone, DVM, known to all in APDA as Paul, died suddenly on Oct. 5, on Staten Island. Dr. Maestrone was APDA's director of scientific and medical affairs for 21 years.

“Dr. Maestrone brought a wealth of knowledge and dedication to the position,” said APDA president Joel A. Miele Sr., PE. “He was a Fulbright Scholar, industry research leader, and holder of four U.S. patents before joining our organization and immediately put his talents and creativity to work to expand and strengthen it.”

Under Dr. Maestrone's direction, APDA created nine Centers for Advanced



**Paul Maestrone,**  
**DVM, Director**  
Scientific & Medical Affairs  
1987-2009

Research, 60 Information & Referral Centers, expanded its support group network to more than 1,000, and funded millions of dollars in Parkinson's disease research and patient/caregiver support and education programs.

Dr. Maestrone's interests were global in scope. At the time of his death, he was president of the World Parkinson Disease Association, which he created in 1998. One of his proudest awards came in 2005 when the Italian town of Vigevano presented him its emeritus Citizen Medal for his contributions to people with Parkinson's disease.

He leaves his wife of 53 years, Sophia, a son and two daughters, seven children and two great grandchildren. ■

## The Role Of Dopamine Agonists In Parkinson's Disease *continued from page 1*

differences in binding affinities are clinically, there is no doubt that some patients respond better to one agonist than to another.

This class of medications acts directly on the dopamine receptors without the need for metabolic conversion, transport, storage and then release. Furthermore, because of their longer half-life (especially Requip XL) compared to L-dopa, there is less fluctuation of blood levels, which appears to be a significant factor in reducing the probability of the future development of motor fluctuations (e.g., “on-off” and “wearing off” phenomenon) and dyskinesias. Thus, the concept of more continuous dopaminergic stimulation should remain a guiding principle in the treatment strategies in PD.

The dopamine receptor agonists were originally employed as adjunctive, or “add on” medications to supplement the use of L-dopa when further dopaminergic effect was desired or when complications of treatment were encountered such as dyskinesias, “wearing off,” and motor fluctuations.

Dopamine receptor agonists continue to be used in this way today; however, the effectiveness of using agonists as monotherapy in early PD is now well established. The use of Mirapex, Requip and Requip XL as monotherapy in early PD has been documented to provide clinical effectiveness for a number of years in some individuals, thus allowing a significant delay in the use of levodopa. This latter point is very im-

portant for all individuals with PD, but especially in the young-onset PD group, as this group is at greater risk for the development of motor fluctuations and dyskinesias after relatively short-term use of levodopa. Levodopa-sparing strategies should be taken advantage of whenever possible.

As a group, the dopamine receptor agonists have a significantly increased safety margin with regard to the production of dopaminergic motor side effects such as dyskinesias and motor fluctuations compared to L-dopa. In general, the newer agonists (Mirapex, Requip and Requip XL) are less likely to generate side effects, nevertheless, dyskinesias, confusion and hallucinations are certainly possible with all of these drugs. Furthermore, leg swelling and orthostatic hypotension may also occur. Of note, these drugs can also induce sleepiness and, although rare, sleep attacks and must be used with great caution in patients who are driving.

Most recently, the dopamine receptor agonists have been shown to result in a relatively uncommon side effect called dopamine dysregulation syndrome, i.e. compulsive behavior. This problem can occur in less than 5 percent of patients taking these drugs but can be quite serious. The compulsive behavior can take many forms but most commonly involves gambling, shopping, eating and sexual behavior. ■

*Dr. Rezak is the medical director of APDA National Young Onset Center and The APDA Illinois Information and Referral Center, Central DuPage Hospital, Winfield, Ill.*

## VA Expands Benefits Status for Vets with PD Exposed to Agent Orange

Veteran Affairs (VA) Department Secretary, Eric Shinseki, announced that Parkinson's Disease (PD) has been added to the presumptive status list for Vietnam veterans who were exposed to the herbicide, Agent Orange. Presumptive status makes it easier to obtain disability benefits, and means that veterans will not have to prove an association between their disease and their military service.

Under the new law, veterans who served in Vietnam between 1962 and 1975 (including those who visited Vietnam even briefly), and who have a disease that VA recognizes as being associated with Agent Orange, are presumed to have been exposed to Agent Orange.

The VA pays disability compensation to Vietnam veterans who have injuries or diseases that began in, or were aggravated by, their military service. The monthly payment amount is determined by the

veteran's combined rating for his/her service-connect disabilities based on the severity of the disability.

The new status means that there is available evidence to support a possible link between Agent Orange and PD. The veteran needs to provide a medical diagnosis of PD, evidence of service in Vietnam, and medical evidence that the disease began within the deadline.

The VA's Web site, [www.va.gov](http://www.va.gov), includes a review of the eligibility for benefits for veterans who served in Vietnam from 1962 to 1975 and those who were exposed to herbicides outside of Vietnam. Click on the link to Health Care Benefits / Eligibility or go to [www.publichealth.va.gov/exposures/agentorange/benefits.asp](http://www.publichealth.va.gov/exposures/agentorange/benefits.asp). The “VA's Guide to Agent Orange Claims” is available by calling a regional VA office or 1-800-827-1000, or by visiting [www.vba.va.gov/bln/21/benefits/herbicide/AOOno3.htm](http://www.vba.va.gov/bln/21/benefits/herbicide/AOOno3.htm). ■



By **ENRICO FAZZINI, DO, PhD**

Associate Professor of Neurology  
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**Q.** My wife was recently diagnosed with Parkinson's disease. She has a tremor in her left arm and she has no other problems with walking or taking care of herself. She is 59 years old and has been healthy, although she has been depressed since her mother died and takes Remeron to help her sleep. Does she need to take anything?

**A.** It sounds like she does not need to start L-Dopa (Sinemet). There are four choices which remain: 1) Azilect or selegiline which may have a neuroprotective effect, but cannot be taken with Remeron, 2) Amantidine, which may help the symptoms, 3) Anticholinergics like Artane or Cogentin, which may help the tremor but could cause memory impairment and excess dryness and constipation and 4) dopamine agonists like Mirapex or Requip XL, which would treat the symptoms and may have a neuroprotective effect. I would start the dopamine agonist, take her off Remeron and then eventually start Azilect.

**Q.** I have Parkinson's disease for eight years. I have side effects from every medicine that has been tried on me except for Sinemet, but it doesn't work right and I never know whether I am going to be able to go out. What can I do?

**A.** The problem with using Sinemet is that it doesn't work smoothly as the disease progresses.

You could try combining Sinemet CR with the immediate-release Sinemet and be careful about the timing of your doses especially in regards to eating. You might be a candidate for the deep brain stimulation.

**Q.** I am 77 years old and I have been diagnosed with Parkinson's disease. I am worried that I will get paralyzed and be in a wheelchair. Does that have to happen?

**A.** Relax! Parkinson's disease never causes paralysis. What occurs over a long period of time is a gradual impairment of balance. Make sure that you start therapy with a neurologist trained in treating Parkinson's disease. You can request a list of neurologists specializing in the treatment of Parkinson's disease from your closest APDA Information and Referral Center.

**Q.** My dad is 90 years old and was diagnosed with Parkinson's three years ago. Although he does not have debilitating tremors, he feels "internal" tremors, has a very shuffling gait and a blank emotionless stare. He has been treated with traditional medications – Stalevo, Symmetrel, Mirapex, Sinemet, Comtan – over the course of time. He now suffers hallucinations from any and all of these medications, so everything has had to be stopped.

His MD has suggested retrying Sinemet and adding Seroquel (anti-hallucinogenic agent) to reverse

the hallucinations. It sounds very risky to me and we are resisting. It is unsafe to have him hallucinating, when he is otherwise totally alert and oriented.

The other suggestion by his MD is to try Inderal (Propranolol). We did try a low dose, but his pulse dropped to 42 as he routinely runs at about 50.

My question is whether you have heard of these recommendations and/or if you are aware of any Web site that might lend me more information about either the Seroquel addition or the use of Inderal for Parkinson's disease.

**A.** Sinemet (carbidopa-levodopa) has the most benefit on the symptoms of PD and the least side effects in terms of causing hallucinations. The lowest dose possible should be tried to help relieve the rigidity if only to help him breathe and decrease the risk of choking and falling. Seroquel is excellent in decreasing the hallucinations and should be given at bedtime. One more suggestion: using medications to improve cognition - such as Exelon or Aricept - will decrease the chance for the Sinemet to cause hallucinations. I would have your dad on Sinemet 25/100, ½ tablet at breakfast and lunch, Seroquel 25 mg at bedtime and either 10mg of Aricept or the 9.4 mg Exelon patch daily. ■

By K.G. Whitford

## Hands-On Advice For PD Patients



*Linda Parks massages Susan Ernst's hands before her manicure.*

Living with Parkinson's disease should emphasize the word "living" not "Parkinson's disease."

One of life's little luxuries for most women (although men, too, have learned the secret) is the pampering effect of a manicure and pedicure and doesn't automatically need to be

crossed off because of a tremor or two.

Linda O'Connor, APDA's Cedars-Sinai Medical Center Information & Referral Center coordinator in Los Angeles, gave some advice to nail salon owners and technicians several years ago in the professional publication "Nailpro."

"Having a manicure and pedicure can be a great stress reducer," Linda says, "and in most cases a person with PD need not forego them. In fact, they can be beneficial."

Linda suggests that you first evaluate your situation. Ask yourself if your symptoms are tremor or muscle stiffness, if you have predicable "on" times, if you can judge how long your medication will take to "kick in"

and how long it can be counted upon to minimize your symptoms. With this in mind, go to a salon and talk with the owner and ask if you can be assigned a regular tech, who will work with you.

If you don't feel comfortable at the first salon, go to another. They abound.

"When you have found a tech you like, schedule an appointment and take your meds before going to the salon," Linda suggests. She also recommends having medication with you. "Alert your tech that you may need her assistance, and ask for a glass of water at the workstation."

Most manicures and pedicures include a massage at the end. Suggest it before or during to relax tight muscles and ease stiffness and cramping. You may also request filing your nails rather than clipping if your tremors are unpredictable or you are uncomfortable with the tech's using sharp implements.

Salon owners report that the most difficult part is polishing nails. Some techs use separators between fingertips to keep fingers from touching each other, similar to what is used for a pedicure. The easiest solution is to use very light or clear polish, which can be easily touched up without showing.

"The psychological lift of seeing your pretty hands and feet can be better than medication," Linda says. ■

## Young Onset Conference

By Julie Sacks

Director, APDA Young Onset Center

The APDA National Young Onset Center is embarking on a new and exciting project, an interactive resource guide which will address many of the traditional areas of concern for people with Parkinson's of all ages. It will also include resources for less commonly researched topics of particular interest to young people including support services for children/teens of a parent with PD, health/disability insurance, prescription drug assistance programs, etc.

Younger people, who face a longer period of time living with Parkinson's often have concerns about their current and future financial situation. This project allows us to focus on addressing those concerns by identifying no-cost or low-cost

resources that will make it easier for people to find information and answers to some of their most challenging questions and situations.

We all know that the Internet has changed the way we research, think, and even behave when it comes to communicating and learning. We are currently exploring the latest technology and will then determine which vehicle will allow us to create the most robust resource guide.

We would like to incorporate a user-feedback mechanism so patients, family members, and healthcare professionals may contribute to the resource guide, thereby building and expanding its content over time.



*Young onset conference participants join in an exercise session.*

This project reflects APDA's ongoing commitment to the young onset PD community and to empowering people with PD, especially those who have limited resources, to manage their own health and healthcare more effectively. ■

## AROUND THE COUNTRY

### In the West



Mary Mowry, founder of the Parkinson's Disease Association of San Diego, and the first coordinator of APDA's San Diego Information & Referral (I&R) Center, and the center's medical director, Dr. Dee Silver, light the Ray of Light Candle, in memory of those who had, or continue to struggle with, the many challenges of Parkinson's disease, at the seventh annual Ray of Hope Dinner. The event was attended by more than 200 people. Mary, who is 80 years old, has established a foundation in memory of her husband, Robert, and has been involved in helping Parkinson's families since 1980.

Suzanne Cameron of Magnolia, Wash. was so taken with the movie "Julia and Julie" that she used it as the theme of her 10th annual fundraising dinner, which have raised approximately \$200,000 for PD research. Suzanne is the Washington chapter's co-president and noted on the invitation to "La Cordon Bleu Magnolia" that chef attire was optional, but pearls required. The gourmet meal including beef bourguignon and bouillabaisse was served to 160 guests at seven food stations.

### In the Northeast

Always in the vanguard, the Massachusetts Chapter introduced a day-long seminar for yoga teachers last month that included strategies and safety tips they can use to guide their students who have limitations associated with movement disorders. Cathi Thomas, RN, Boston I&R Center coordinator, noted that many people in the PD community are interested in yoga's benefits, and teachers appreciate gaining insight into the challenges these students face. Renee LeVerrier, who has a PD diagnosis and is the author of "Yoga for Movement Disorders: Regaining Strength, Balance and Flexibility for Parkinson's Disease and Dystonia," and Tamara Rork DeAngelis, a senior physical therapist

at Boston University's Sargent College, led the seminar with Cathi in September. Fifteen yoga instructors participated in the event at the Yoga Center of Newburyport.

Joel A. Miele Sr., APDA president, noted that a person usually had to die or retire to have a tribute similar to the one for Dr. William Hamill in October. Fortunately, the medical director for the Vermont I&R Center did neither but generated that kind of gratitude from patients, co-workers and the community. The head of Vermont University's College of Medicine's neurology department took some good-natured ribbing for his signature bow ties, but was serious when thanked for his contributions

to the center and his many years of serving neighboring New Hampshire's Parkinson's community before APDA opened an I&R Center at Dartmouth-Hitchcock Medical Center. Proceeds from the event, which included a golf outing and gala dinner, benefited the Robert W. Hamill Respite Fund for Parkinson's Families.



*Dr. Hamill joins in the festivities during a Vermont Chapter event.*

### In the Southeast

After being diagnosed with PD and being forced to retire from teaching in 1997, Mary Foertsch of Pinellas County, Fla. developed an interest in gemstones. She studied the folklore, traditions, and purported healing powers attributed to each stone and how the different stones could be combined and presented in order to enhance both their physical and spiritual properties. She began designing and making her pieces, in 2004 as therapy, but it has since become her passion. At first she gave her pieces away, but at the suggestion of friends, she began to sell them. Ten percent of each sale goes to APDA. Because of her disability, her output is small but each piece is uniquely designed. You can see her work at her Web site [www.protopage.com/jazzandgems](http://www.protopage.com/jazzandgems). In addition to fashion, Mary has contributed more than \$1,000 for PD research and patient support. ■

## Newcomers Add Research Support For APDA's 2009 Walk-a-thons

Almost half a million dollars will go to Parkinson's research because dedicated volunteers walked, ran, and biked around the country at APDA walk-a-thons. The walk-a-thon is APDA's official event to raise awareness, and funds are restricted to scientific research to discover the causes and cure for PD.

Walks vary in size and format, but every one helps APDA to meet its mission, to "Ease the Burden – Find the Cure."

The Central Susquehanna Valley Chapter launched what it plans to be an annual walk appropriately by ringing a victory bell. The event took place at the Geisinger HealthSouth Rehabilitation Hospital in Danville, Pa., where the chapter is located, and partici-

pants walked around the building while others sat and shared stories.

Another first walk, a "Hull of a Race," organized by physical therapist and runner Lori Griffith, who also founded the Mark Twain Area Parkinson's Support Group, took place in, of course, Hull, Mo. Here the terrain included fields of corn and soybeans.

In Cincinnati, Ohio, more than 250 people participated in the Tri-State Parkinson's Wellness Chapter inaugural 5K Steady Strides in the Voice of America Park in West Chester.

The newcomers are off to a good start, raising \$15,000 for research. ■



*Sharon Zboray, the chapter vice president, and Hazel Nachway, whose late husband had PD, ring the victory bell to start the Susquehanna Chapter's first walk.*



*Racers line up under sunny Cincinnati skies for the Tri-State Parkinson's Wellness Chapter's inaugural 5K race.*

## Parkinson's Associated Risk Study (PARS)

The PARS study is seeking first-degree relatives (sister, brother, parent, child) of people with Parkinson's disease (PD). The goal of the study is to see if early signs of PD can be detected and predict an increased risk for PD.

The loss of smell is a common first symptom in people with PD and frequently occurs prior to the onset of motor symptoms. The UPSIT (University of Pennsylvania Smell Identification Test), which is a test of sense of smell, will be the initial test to be evaluated.

Individuals interested in participating and are eligible will be sent a smell test and a brief questionnaire in the mail. After the smell test and questionnaire are returned by mail to the PARS study center, participants may be asked to visit a study center closest to them for evaluation by one of the study investigators. For more information, you can contact the PARS Study Team toll free at (877) 401-4300, go to the study Web site at [www.parsinfosource.com](http://www.parsinfosource.com) or email to [parinfo@indd.org](mailto:parinfo@indd.org). ■

## Gloria Capecelatro's Caregiving Plan Is to Live One Loving Day at a Time

APDA's Web site ([www.apdaparkinson.org](http://www.apdaparkinson.org)) readers will recognize John and Gloria Capecelatro from the home page. The Capecelatros live in Orange, Conn., and Gloria was the 2008 Connecticut Chapter/APDA Caregiver of the Year.

John was active in his family's wholesale greenhouse business until diagnosed with PD in 1991 and is currently dependent upon a wheelchair and feeding tube, but Gloria focuses on the positives of each day. "There are good days and bad days, and if I can get through this bad day, tomorrow may be a good one," she says.

Both are from farming families and she remembers how her father and John's father were telling each other about their children and decided there might be match. "But," she says, "nobody was going to tell me what to do!" Well, 64 years and three children later, nobody still tells her what to do, but she agrees that their fathers did know best. "It was obviously destiny."

Caregiving, however, was unfortunately not new to Gloria when John was diagnosed. Their youngest daughter, Mary Lee, was diagnosed with Lupus when she was just 17 years old, and Gloria cared for her until her death eight years later.

"I almost lost my faith then," she remembers, "but now my religion is my strength. I tell people that the Lord gives you a deck of cards when you are born, and you play the game out as best you can."

Focusing on a lifetime of wonderful memories also helps her. She remembers trips to Italy (including

being at the Vatican when the Pope arrived in his Popemobile), Alaska and Hawaii and cruises that she and John have taken. "We loved to play golf together up until 2002. When we could, we walked, and then we used a cart until John just couldn't balance anymore," she says.

Last month was National Caregivers Month, but people who are responsible for the care of a loved one, especially a loved one with a progressively degenerative disease, know that every day is another day of challenges.

The Capecelatros' pride and joy are in their son, Richard, and daughter, Carol, their five grandchildren, and two great-grandchildren, all of whom live nearby, except for their granddaughter, Mary, who is teaching English and working for her PhD in comparative literature at the Sorbonne University in Paris.

Gloria dismisses the enormity of her caregiving role. "John is as wonderful a patient as he is a husband. He never complains, never feels sorry for himself. When I get frustrated at myself for not having the strength to physically help him more, I say to myself, 'if he can handle this, so can I.'"

And she certainly can. ■



### APDA Launches Caregiver Coordination Web Service

Even caregivers with friends and neighbors to help with chores, doctors' visits and the myriad tasks involved in caring for a loved one with a progressive, degenerative disease, find that coordination can be another demanding duty.

Visitors to APDA's Web site will find a new link on the home page, which when clicked, will provide a free new service to help "Ease the Burden."

"Half of our mission is patient and caregiver support," said APDA executive director Joel Gerstel, "and we believe that this new e-tool for caregivers will be a valuable assistance in garnering help to fulfill their many demands. How often has a friend sincerely offered general help, only to be told, 'Oh no, I'm fine?'" Someone who truly wants to help may now go online to that caregiver's dedicated page to see what tasks need to be done, and volunteer to do one or more without being asked, he said.

"Lotsa Helping Hands" is a caregiver coordination service that allows for the creation of "circles of community" that may include family members, friends,

co-workers, neighbors, anyone who would like to volunteer to help. It's an easy-to-use private group calendar specially designed for organizing helpers, where everyone can pitch in with meal deliveries, rides and other tasks necessary for life to run smoothly during demanding healthcare times.

Community members may look at the site to see which tasks the caregiver would appreciate help with on a specific date – rides, shopping, meals, housecleaning, visits, errands – and sign up on line. The caregiver then removes that task from the "needed" list.

The site also facilitates communications among community members by posting well wishes, photos, blogs, or message boards. It also provides for the secure storage and retrieval of vital information such as emergency contacts, medications, legal and financial records.

"We believe this program can be a major aid in reducing caregiver stress, easing financial burdens, impacting work, and managing daily caregiver tasks," Mr. Gerstel said. ■

## RISK OF FALLING

Parkinson's patients often have balance impairment and are at increased risk of falling. According to Dr. Lynn Struck, medical director of the APDA I&R Center in Des Moines, Iowa, the Academy of Neurology recently developed parameters for screening and assessing risks for falling patients. This report says that each year more than 16,000 deaths result from falls. Three quarters of these occur in individuals over 64 years of age. There are nearly 500,000 hospitalizations and 1.8 million emergency department visits annually because of falls.

There are several specific risk factors for falling. These included advanced age, muscle weakness, gait and balance difficulties, visual deficits, arthritis, depression, cognitive impairment, and impairment of activities of daily living. Also, there are several medications that pose an increased risk.

There are also several guidelines to help prevent falling such as the proper use of assistive devices, reducing medications as much as possible, and changes in individuals' living situations.

Each individual should discuss his/her concern on balance problems with the attending physician so appropriate recommendations can be made to minimize this risk. ■

*As reported in American Academy of Neurology, Vol. 70, 2008, pp 473-479*

## Recruitment for SURE-PD Research Study

SURE-PD (Safety and Ability to Elevate Urate in Early Parkinson's Disease), a new clinical study, has begun enrollment at sites across the United States. The study's main goal is to determine whether inosine (a potential brain protectant) can safely increase the body's levels of urate, a natural antioxidant in humans. Based on previous research findings that Parkinson's disease tends to progress more slowly in people who have higher urate levels, Michael A. Schwarzschild, MD, PhD and his colleagues in the Parkinson Study Group hope that the results of SURE-PD will set the stage for future investigation into whether inosine can slow the progression of Parkinson's disease.

If you are a recently diagnosed Parkinson's disease patient not yet on medication, you may be eligible to participate in the SURE-PD study. If you interested in participating or would like more information, call the Parkinson Study Group at 888-887-3774. Additional information can be found on these web sites [www.parkinsonstudy-group.org](http://www.parkinsonstudy-group.org), [www.clinicaltrials.gov](http://www.clinicaltrials.gov) or [www.pdtrials.org](http://www.pdtrials.org). ■

*Dr. Schwarzschild, of Massachusetts General Hospital and Alberto Ascherio, MD of the Harvard School of Public Health lead the SURE-PD research study.*

## Incidence of Parkinson's Disease in Pennsylvania

The objective of this study conducted in Philadelphia was to determine the incidence of Parkinson's disease (PD) and the effects of race/ethnicity, other demographic characteristics, geography, and healthcare utilization on the probability of diagnosis.

The authors used the Pennsylvania state Medicaid claims database from 1999 to 2003 to identify newly diagnosed cases of PD among the 182,271 Medicaid-enrolled adults age 40-65; 319 cases of PD were identified. The four-year cumulative incidence of PD was 45 per 100,000; 54 per 100,000 among whites, 23 per 100,000 among African-Americans and 40 per 100,000 among Latinos, corresponding to a relative risk of PD of 0.43 for African-Americans compared to whites.

After adjusting for age, gender, geography,

reason for Medicaid eligibility, and average number of visits, African-Americans were still half as likely to be diagnosed with PD as whites. Older age, more healthcare visits and Medicaid eligibility because of income alone also were significantly associated with PD diagnosis, while gender was not. Observed racial differences in incidence of PD are not explained by differences in age, sex, income, insurance or healthcare utilization, but still may be explained by biological differences or other factors such as education or aging beliefs. Better understanding of the complex biological and social determinants of these disparities is critical to improve PD care. ■

*As reported in Movement Disorders Vol. 24, No. 8, 2009 pp. 1200-1205*

## TIPS FOR ENJOYING THE HOLIDAYS AND CARING FOR YOURSELF

Life isn't over with the diagnosis of Parkinson's disease, and should not diminish the joys of the holiday season, even with its increased stresses of extra preparations and complicated family dynamics. This year try to keep your holiday stress to a minimum by prioritizing what is important to you and then planning how you will get it done. Here are some helpful tips to help you enjoy the holidays:

1. Share your laughter and joy. Your life is different but the joy is still there.
2. Make plans for Christmas, Chanukah, and New Years. Making plans gives you something to look forward to and keeps you engaged in life.
3. Think about what family rituals you may have for celebrating the holidays and look for ways they can be adapted if need be to any physical limitations. It's important to find ways to celebrate that are meaningful and enjoyable to you.
4. Ask for help if needed and pace yourself with activities, especially if you are experiencing fatigue.
5. Include yourself in decisions related to plans and what you can and can't do. Don't give up any more control that you have already had to.
6. Avoid taking on unnecessary extra chores and tasks. Simplify whenever possible – JUST SAY NO!
7. Avoid unrealistic expectations; it's the surest way to disappointment. Accept that your holidays will be what they will be.
8. Spend time with people who make you feel strong and supported. You can choose with whom you spend your holiday. The holidays are meant to be a celebration of life.
9. Focus on reducing as much stress as possible by allowing time for rest and relaxation. The first step is to get into a regular pattern of sleep. Set a regular bedtime; avoid watching the news, a warm bath and possibly medication should help.

Many people find meditation a helpful tool in stress reduction. Meditation comes in a variety of forms from simple breathing exercises to a guided imagery technique. Whichever form of relaxation works best for you, the key is to gain focus and control over your own thoughts.

Kerry Gillespie, the director of the Staten Island University Hospital (SIUH) Center for Complementary Medicine, says, "Our thoughts are powerful and if we can't exercise control over them, they will more often than not move in a negative direction. It is not to diminish the chronic nature of this disease, but your attitude will affect the quality of your life and the lives of people who love you."

Remember that laughter and positive, hopeful thoughts are good for your health, and that the holiday season is one of love and affection.

If you would like to try a five-minute meditation exercise to see if you like it, call the SIUH "Relax Line" at 781-226 CALM (2256). ■

*This article is based upon information from APDA's Fountain Valley, Cal., and Staten Island, N.Y. Information & Referral Centers' newsletters.*

### Give a Gift of Hope

Holidays are gift-giving times and a contribution to APDA is a gift of hope to 1.5 million Americans with PD and their families. An "in honor" gift means no store lines, worrying about color and size, or gift wrapping, and it is tax-deductible. Contributions can be made by call 800-223-2732, on our Web site, [www.apdaparkinson.org](http://www.apdaparkinson.org), or sending a check to APDA, 135 Parkinson Ave., S.I., NY. ■

## SWALLOWING PROBLEMS IN PARKINSON'S DISEASE

An aspect of Parkinson's disease (PD), which does not often receive attention, is the loss of involuntary movement such as armswing while walking, blinking, facial movements and swallowing.

The medical term for swallowing difficulty is dysphagia. Dysphagia and dribbling are more common in the later stages of PD; however, they can occur earlier when associated with other Parkinson disorders.



The loss of the autonomous swallowing movements leads to the pooling of saliva in the mouth, and there is also a tendency for the closure of the lips to be impaired

by dysphagia, resulting into dribbling. There is no increase in the production of saliva; however, it is interesting to note that we produce more than a quart of saliva each day.

Most of the saliva is produced at mealtimes, and the swallowing of food can often help someone with dysphagia, since dribbling may be reduced. With the constant production of saliva, however, between meals, even though at a reduced rate, dribbling can be hard to control.

Swallowing at mealtimes is an issue by itself, with as many as 40 percent of people with dysphagia experiencing 'silent aspiration.' This is when food or drink enters the trachea without eliciting a reflexive cough, thus causing pneumonia.

The following problems may develop during mealtime:

- Swallowing hesitation or inability to swallow
- Food sticking in the throat
- Swallowed food backing up into the nose
- Choking
- Need of repetitive swallowing
- Throat clearing

- Coughing after swallowing
- Need to "wash down" food with drink

Because weight loss is common in Parkinson's, it is important to keep an eye out for any eating difficulties and report them to your health professional.

Surprisingly, chewing is usually not a problem. It is more common for eating to be very slow, than for people with dysphagia to experience choking. However, if choking does occur, posture while eating or drinking is important – try to sit upright with the head bent forward.

In order to make mealtimes easier, it might be necessary to change your diet with the help of your medical professional. The following foods may be easier to swallow:

- Milk, cream, custard, and yogurt
- Omelets and pancakes
- Casseroles, soup, and soft boiled rice
- Banana and soft fruits

In a few people, usually when Parkinson's has been present for 10-15 years, dribbling is a major problem. It can be socially embarrassing as the person with Parkinson's is well aware of the dribbling but cannot react quickly enough to stop it from occurring.

Medications to dry the mouth do not seem to reduce the dribbling unless the mouth is made unacceptably dry or there are side effects such as blurred vision. The best management may be to use a small towel and/or tissues. In social situations it may be helpful for a caregiver or loved one to sit close to the person with Parkinson's and quickly wipe away any dribble.

Issues with swallowing and dribbling may seem embarrassing or troublesome, but with the help of your health professional and loved ones, changes can be made to make mealtimes and social events easier. ■

*This article was adapted from the "Parkinson's Fact Sheet on Swallowing and Dribbling" published in the June 2009 issue of the Parkinsonian, the magazine of Parkinson's New Zealand.*

# Educational Material

Most APDA publications can be downloaded free from our Web site, [www.apdaparkinson.org](http://www.apdaparkinson.org), publications page.

The new APDA e-newsletter provides timely news about all aspects of PD and a helpful "Tip of the Month." The newsletter is free, and you can unsubscribe any time. Sign up on the APDA Web site's home page.

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 APDA Information and Referral Centers throughout the United States.



## BOOKLETS

(order by letter)

- A. Parkinson's Disease Handbook (English, German, Italian, Spanish)
- B. Young Parkinson's Handbook
- C. Be Active
- D. Be Independent
- E. Speaking Effectively
- F. Good Nutrition
- G. Aquatic Exercise for Parkinson's Disease
- H. 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 Disease
- 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 Disease
- 21. Dr. Andrew Weil's Recommendations for Healthy Aging
- 22. Depression and Parkinson's Disease
- 23. Incontinence and Parkinson's Disease
- 24. Employment and Parkinson's Disease

## FLYERS

- 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

## WEB SITES

- [www.apdaparkinson.org](http://www.apdaparkinson.org)
- [www.youngparkinsons.org](http://www.youngparkinsons.org)
- [www.apdawest.org](http://www.apdawest.org)
- [www.apda.org](http://www.apda.org)

## DVD

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

Materials concerning research in the field of Parkinson's disease, and answers to reader's 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.

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