

## The American Parkinson Disease Association

A Quarterly Newsletter ©2006  
by The American Parkinson  
Disease Association, Inc.

Paul Maestroni, DVM,  
Director of Scientific and  
Medical Affairs,  
Editor

Vincent N. Gattullo  
President

Joel Gerstel  
Executive Director

## INDEX

Parkinson's Disease Medications	P. 1
President's Message	P. 2
Restless Legs Syndrome & Pramipexole	P. 2
Communicating with Your Pharmacist	P. 3
Q&A	P. 4
F.Y.I.	P. 5-8
Speech & Voice Problems in Parkinson Disease	P. 9
Traveling & Your Meds	P. 10
To Drive or not to Drive?	P. 11
A New Way to Help People Get Prescription Medicines	P. 11
After Your Diagnosis	P. 12
Steps — A New Clinical Study	P. 12
Educational Material	P. 12

### Main Office:

135 Parkinson Avenue  
Staten Island, NY 10305  
1-800-223-2732  
www.apdaparkinson.org  
apda@apdaparkinson.org

### West Coast Office:

10850 Wilshire Blvd.  
Los Angeles, CA 90024  
1-800-908-2732

## Parkinson's Disease Medications

If I have heard it once, I have heard it a hundred times; and I'll bet that, if you haven't asked it, you have at least thought about it! But what kind of response can be given? How can we in the medical profession get the dopamine (and other neurotransmitter) levels to near normal levels, if we do not push more pills? And what kind of pills?

Why do you have to take some pills every three hours, some every four hours, some every six hours, some every eight hours, some every 12 hours and some only once a day? Why some with food, some without food? It is a very confusing and complicated way to live, isn't it?

Some answers are easy; others are not. Maybe it would help to know which the active principle of medication is and some simple basics about elimination of medication from your body.

When a medication (L-Dopa, for example) doesn't last long in the body, you must take it very frequently, but then, you must make sure that it gets absorbed, and transported to where your body needs it. "And make it work quick Doc". Hmmmm. Okay; what is currently available to help?

**Apomorphine** (Apokyn®) is given by injection, and kicks in rapidly, usually in 5 to 15 minutes but also wears off rapidly, usually in less than an hour.

Don't like injecting yourself every hour or so? Okay, looks like we are back to pills: The orally disintegrating carbidopa/levodopa **Parcopa**®. Nice to take because you don't need water; but may not kick in any earlier than



regular carbidopa/levodopa (Sinemet®), and doesn't last any longer. *Advantage:* Oral disintegration.

**Regular Carbidopa/Levodopa** (Sinemet®) kicks in within 30 minutes

most of the time, it may last 3-4 hours (longer if you are recently diagnosed). *Advantage:* Gold standard of Parkinson therapy.

**Sustained Release Carbidopa/Levodopa** (Sinemet CR®). Kicks in 40-60 minutes, may last four to eight hours depending on how long you have had Parkinson's. *Advantage:* Continuous release for longer period of time.

**Dopamine Agonists** Pramipexole (Mirapex®), Ropinirole (Requip®), Pergolide (Permax®), Bromocriptine (Parlodel®). *Advantage:* Last longer in the body.

**COMT Inhibitors** Entacapone (Comtan®), Tolcapone. (Tasmar®). Take with each dose of Sinemet (Comtan), or three times a day (Tasmar). *Advantage:* Make Sinemet last longer.

**Selegiline** (Eldepryl®). One in the am, one at noon. *Advantage:* Makes Sinemet last longer.

**Rasagiline** (Agilect®) not yet available in USA. One a day. *Advantage:* Makes Sinemet last longer, once a day, it has the same benefit as Comtan.

"Yeah, yeah: I know about all the pills. What other options could there be?"

**Patch:** There are patches for pain medication, blood pressure medication, and other medications. Fortunately, a patch for a dopamine agonist has been developed, and is in the process of approval by the FDA. Antic-

*continued on page 10*



## P R E S I D E N T ' S   M E S S A G E

Dear Reader,

We are well on our way into a new year, and as always, a year in which we hope to see a cure for Parkinson's disease discovered, and APDA is doing its part to make that happen.

In 2006, APDA is escalating its research funding by increasing the amount of the George C. Cotzias Fellowship from \$70,000 to \$80,000 annually for three years, and extending the Roger C. Duvoisin, MD Grant to two years from its present one-year award. We are also increasing support to our seven centers for advanced research (three of which are also Udall Centers for Excellence receiving \$1 million each year from the National Institutes of Health) from \$90,000 to \$105,000 annually. Our co-operative funding with the Michael J. Fox Foundation has saved the nation's only state PD registry in Nebraska, and we will continue to encourage the work of outstanding neurologists with the Fred Springer Award this year going to Dr. David Eidleberg (a former Cotzias recipient) of North Shore-Long Island Jewish Health System, which you will read about on page 8.

### RESTLESS LEGS SYNDROME & PRAMIPEXOLE

It was reported at the 19th annual meeting of the Associated Professional Sleep Societies (APSS) in June 2005 in Denver, Colorado that the dopamine agonist, pramipexole, substantially reduced the severity of Restless Legs Syndrome (RLS) symptoms in patients receiving this medication.

The results were obtained from two clinical studies investigating the effects of pramipexole in RLS patients.

Pramipexole (Mirapex ®) is currently approved for the treatment of the symptoms of idiopathic Parkinson's disease, as monotherapy or in combination with levodopa, and is being evaluated in clinical trials as a potential treatment for reducing the symptoms of RLS. RLS is a common, but poorly recognized and under-treated neurological disease that predominantly affects adults.

The most commonly reported adverse effects of pramipexole in early and late Parkinson's disease are dizziness, dyskinesia, extrapyramidal syndrome, headache, insomnia, somnolence, and nausea. Hallucinations and postural (orthostatic) hypotension may occur. Patients have reported falling asleep without perceived warning signs during activities of daily living, including operation of a motor vehicle. ■



*President Vincent Gattullo, seated, during APDA's national headquarters dedication posed with founding family members Sophia Esposito Maestroni and Jay Springer, right. Executive director Joel Gerstel and guests former Gov. and Mrs. Mario Cuomo are on the left.*

conferences, which had to be paid for in the past. These financial efficiencies translate into more available funds for research, education and patient and caregiver support.

The dedication itself was a great success with former New York State Governor Mario Cuomo attending with his wife Matilda, who is a former member of our board and was the guest speaker. Photos of the event are on page 5.

Sincerely,

Vincent N. Gattullo  
President

### "Canadian Drugs" — FDA Warning

According to news media reports the FDA has found that nearly half the imported drugs intercepted recently from four countries were promoted as coming from Canadian pharmacies. Eighty-five percent of those particular drugs were actually manufactured in 27 different countries. The FDA says these findings underscore its warnings that some Web sites for so-called "Canadian" drug orders may sell counterfeit products or even ones that are unsafe and ineffective. [www.fda.gov/bbs/topics/news/2005/new01277.html](http://www.fda.gov/bbs/topics/news/2005/new01277.html) ■

# Communicating with your Pharmacist

**Y**ou have just received a new prescription from your physician, but are not sure exactly how to take it. Whom should you ask? You have a headache and want to take some aspirin but are concerned that it may interact with your other medications. Whom should you ask? You developed a small rash on your arm after taking a dietary supplement and are wondering if they are related. Whom should you ask? The common answer to all of these questions, and many others, is **Your Pharmacist**.

Your pharmacist is uniquely qualified to answer your questions about your prescriptions, over-the-counter medications, and dietary supplements.

When you are going to talk to your pharmacist prepare a list of questions ahead of time; bring a list of **ALL** of your medications, prescription and over-the-counter, any dietary (i.e., herbal) supplement and a list of all your medical conditions. Some of the questions that you should always ask are listed below.

## **What is the name and indication of the medication?**

It is important to know the name, both the brand and generic, of your medication. This is especially important in the case of an emergency or traveling to another country where the same medication may be known by a different brand name. In addition, ask your pharmacist if a generic version of the medication is available. It may be able to save you some money. Knowing the indication, the reason you are taking the medication, is important to verify that this is the correct medication for the symptoms you presented to your doctor. In addition, always asking about medication reinforces the diagnosis and creates confidence in the appropriateness of the therapy.

## **How am I supposed to take it?**

Always make sure you understand how to take the medication. Although a particular dosage regimen may seem straightforward, it may mean something different to different people. For example, is four times a day the same thing as every six hours, or can it be at breakfast (7AM), lunch (12 Noon), dinner (6 PM) and bedtime (10 PM)? In addition, the statement "Take one tablet after meals and at bedtime" may not take into account a patient who is fasting or one who eats six small meals a day.

## **How is it supposed to work and how long it will take for it to show an effect?**

Knowing how the medication works may help you understand why the doctor prescribed this specific medication for you. It is also important to know when you will start seeing an effect. This will help you know if the medication is working or not.

## **What are the major side effects of the drugs? How frequently do they occur? Is there anything that I can do to prevent a side effect or treat one if it occurs? Some of the side effects on the information sheet sound scary.**

All medication can cause side effects, however, not every side effect will occur in every patient. By asking these questions, you will better understand the risk associated with this medication and ways to treat and prevent them from occurring (for example, taking with food).

## **Are there any drug-drug, drug-food, drug-disease interactions I should know**

## **about?**

The medications that you take not only affect your body, but may affect the way that other things affect your body. It is important to ask if there are any interactions among everything you take. This includes dietary supplements (i.e. herbal products containing garlic interact with wafarin), food (i.e., grapefruit juice).

## **How should I store this medication? Are there any other instructions that I need (e.g., shake well, refrigerate)?**

Some medications require storing in the refrigerator and some do not. Many patients still store their medications in medicine cabinets in the bathroom — probably the worst place in the house to keep medicine because of heat and humidity. It is important to know where best to store and use your medication.

## **What do I do if I miss a dose?**

It is important to take your medication as it is directed. However, there may be time that you may miss a dose. Depending on the medication, the answer to this question may be different.

Overall, it is important that any and all of your questions are answered. Your pharmacist is a natural resource for information concerning your medication. Do not be afraid to ask questions: the pharmacist is there to help you! ■

*Adapted from "Tips for communicating with your pharmacist" by E. Hermes-DeSantis, Pharm.D. published in the APDA Sept.-Nov. 2005 Parkinson's Bulletin New Brunswick, NJ.*





# Questions & Answers

Enrico Fazzini, DO, PhD

*Assoc. Prof. Neurology New York University, New York, NY,  
University of Nevada, Las Vegas, NV,  
N.Y. Institute of Technology, Old Westbury, NY.*

**Q:** Are any new medications going to be available this year to treat Parkinson's Disease?

**A:** There are two medications which are scheduled to become available

this year.

Rasagiline is an enzyme inhibitor like selegiline. It is stronger than selegiline and does not break down into stimulants called amphetamines. As a MAO (monoamine oxidase) inhibitor, it decreases the formation of free radicals which build up in the neuron as a byproduct of dopamine metabolism; it therefore may be important in slowing down the progressive of PD.

Rotigotine is a dopamine agonist which will be available as a skin patch. It will therefore be able to deliver a 24 hour a day steady dose of medication which may decrease the "on/off" fluctuations which occur as a consequence of using L-Dopa in patients who have had PD for several years. As a dopamine agonist, it may also slow down the progression of PD.

**Q:** What are the typical side effects seen with medications which are used to treat Parkinson's disease?

**A:** Any medication can have any side effect in anyone. Having said that, the

most common side effects are dyskinesia (involuntary writhing movements) and psychosis (delusions, obsessions, paranoia, hallucinations), lowering of blood pressure, sleep attacks, early awakening, drowsiness, constipation and nausea. Some medications (anticholinergics) can worsen memory and cause urinary bladder retention. It is important that you are cared for by a physician experienced in treating PD in order to avoid or decrease these side effects.

**Q:** My husband has back pain and cramps in his legs. Is this due to Parkinson's disease? His memory is poor

and he wanders around the house at night. Sometimes he thinks there are parties going on in the living room.

What can I do? His neurologist has him on Mirapex Img and Stalevo 100 mg three times a day.

**A:** PD can cause cramping in the arms, legs and neck. This is called dystonia. PD

does not cause back pain, numbness or weakness — these are symptoms of a problem with the nerves as they run in the extremities as they exit the spine. It is most likely due to arthritis in the spine. However, you may notice that when the PD medications work, the muscles are less rigid and the pain is reduced. Also your husband may have dementia with increased sensitivity to side effects (hallucinations) from the medication he is taking. He would probably do better without Mirapex or Stalevo and managed on L-Dopa alone plus the addition of Aricept to help cognitive function and Seroquel to reduce the hallucinations. ■



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

FYI EDITOR: K.G. Whitford

WINTER 2006

VOLUME XII NO. V

## APDA DEDICATES ITS FIRST NATIONAL HEADQUARTERS BUILDING

It took 44 years to become a reality, but on Nov. 20, APDA dedicated its first national headquarters on, appropriately, Parkinson Avenue on Staten Island.

More than 100 celebrants — including members of the founders' families, board members, public officials and patients and their caregivers — heard an inspiring address by former board member and New York first lady, Matilda Cuomo, and impromptu remarks from her husband Mario. Rabbi Michael Melnicke offered the prayer of dedication filling in for the APDA's first president, Dr. Eugene Cohen, who had planned to attend but was hospitalized a week before the event. Champagne and refreshments followed.

Jay Springer, whose father, Fred, served as APDA's president for almost a quarter of a century, and mother, Faye, was instrumental in the organization's beginnings, was present. Sophia Esposito Maestrone, whose

family began the first chapter and whose father and two brothers served as president, was among the happiest celebrants. "I have waited 44 years for this dream to come true," she said. ■



*Rabbi Michael Melnicke, a member of the APDA board of directors, delivers the prayer of dedication.*



*Former APDA board member and NY first lady Matilda Cuomo makes a point during her remarks.*

## APDA AND MICHAEL J. FOX FOUNDATION JOIN TO SUPPORT NATION'S ONLY PD REGISTRY

APDA and The Michael J. Fox Foundation for Parkinson's Research (MJFF) have announced that they will co-fund the Nebraska Parkinson's Disease Registry, the first operational registry for the disease in the United States offering researchers a valuable tool in amassing epidemiological data.

The registry, which has already allowed researchers to measure prevalence in the urban Omaha area (3.48 per 1,000 of those age 60 or more had Parkinson's) versus the less populated agricultural center and western regions (14.82 per 1,000 and 11.50 per 1,000 respectively), was enacted by the Nebraska legislature in 1996 to provide a central data bank of information for research purposes, but was suspended in October 2004 for budgetary reasons.

In the joint three-year commitment, MJFF is to provide \$35,000 to cover current year operations and APDA

will provide \$40,000 to cover two subsequent years of operations.

"The reinstatement of the Nebraska Registry serves as a stepping stone for Parkinson's research, and the Nebraska-specific data can provide scientists with a solid understanding of the role geography plays in Parkinson's disease," said APDA executive director Joel Gerstel.

J. William Langston, MD, chairman of MJFF scientific advisory board's executive committee, said that funding the Nebraska registry will enable researchers to understand Parkinson's trends as they present themselves in a population. "The reinstatement of the Registry and establishment of a similar registry in California make it possible for researchers to collect data on how the disease varies geographically. This is a vital source of information that could help lead to the discovery of the causes of Parkinson's disease," he said. ■

## DAVID G. STANDAERT, MD, PHD

### SCIENTIFIC ADVISORY BOARD MEMBER

David Standaert, MD, PhD., isn't quite certain where his proclivity for science in general and Parkinson's disease (PD) research in particular began, but at age 14 he was working in his father's Georgetown University laboratory and by 17 he had published a paper in a scientific journal.

Perhaps it was partially genetic (his dad was chair of the Georgetown department of pharmacology) and partially subliminal (his grandfather had PD), but whatever it was, it led him to Harvard University, from which he graduated magna cum laude in biochemistry, and Washington University School of Medicine in St. Louis, where he earned a dual MD, PhD. degree.

During his neurology residency at the University of Pennsylvania, still uncertain of a specialty, he was greatly influenced by the work of Drs. Howard Hurtig and Matt Stern at the Penn Movement Disorders Center.



*Dr. David Standaert directs APDA's Advanced Center for Research at Massachusetts General Hospital.*

"I would say that I was drawn into work on Parkinson's by the positive and negative aspects of the disease," he remembers. "The positive is that it is really amazing to see how well levodopa and other drugs can work transforming patients almost before your eyes. The negative side is that this rarely proves to be a truly lasting solution."

It was at this point in 1992 that he made his commitment to working in movement disorder research and went

to Massachusetts General Hospital (Mass. General) to work with Drs. Anne Young and Jack Penny, pioneers in the science of basal ganglia diseases. They, with the influence of Drs. John Growdon and Stephen Fink, who preceded Dr. Standaert as APDA Cotzias Fellowship recipients, led him to PD research.

Dr. Standaert's work has brought millions of dollars to PD research including funding from the National Institutes of Health.

He is the director for both the Mass General/MIT NIH-funded Morris Udall Center of Excellence in PD Research and the APDA Advanced Center for Parkinson Research.

Despite his calm, almost boyish, demeanor, Dr. Standaert's is a hectic life. He spends most of his days in the research lab. He sees patients one afternoon a week in the hospital's PD Center, is an associate neurologist on the staffs of Brigham and Women's Hospital Boston and Mass General, an associate director of Mass General's Movement Disorders Unit, and chairman of its Institutional Review Board. He serves on numerous professional editorial boards and advisory committees of national Parkinson's and other neurodegenerative disease associations and has his name on 75 professional publications. And that's the easy part.

He and his wife, Janet, are the parents of 3-year-old twin boys, who, he admits, "keep us pretty busy."

But three nights a week, from April to October, mental and physical stress are left behind on the shores of the Charles River, where he and fellow member of Community Rowing Inc. take 4- or 8-person shells out on the river. "It is truly a great way to get your mind off of science and medicine for a while." ■

### SEVEN CENTERS FOR ADVANCED RESEARCH

APDA provides approximately \$1 million annually to its seven centers for advanced research at Emory University School of Medicine, Atlanta, GA; UMDNJ-Robert Wood Johnson Medical School, New Brunswick, NJ; Boston University School of Medicine, Boston, MA; University of Virginia Medical

Center, Charlottesville, VA; UCLA School of Medicine, Los Angeles, CA; Washington University Medical Center, St. Louis, MO; and Massachusetts General Hospital, Boston, MA. An additional \$2 million is awarded to individual scientists in the form of fellowships and research grants. ■

### \$30 MILLION TO RESEARCH & GROWING

APDA has contributed nearly \$30 million to PD research, including the 1987 study at Robert Wood Johnson Medical School, which discovered the Alpha Synuclein pro-

tein, central to the pathogenesis of the disease. Contributions can be restricted to research or other APDA programs. Contact us at APDA, 1-800-223-2732. ■

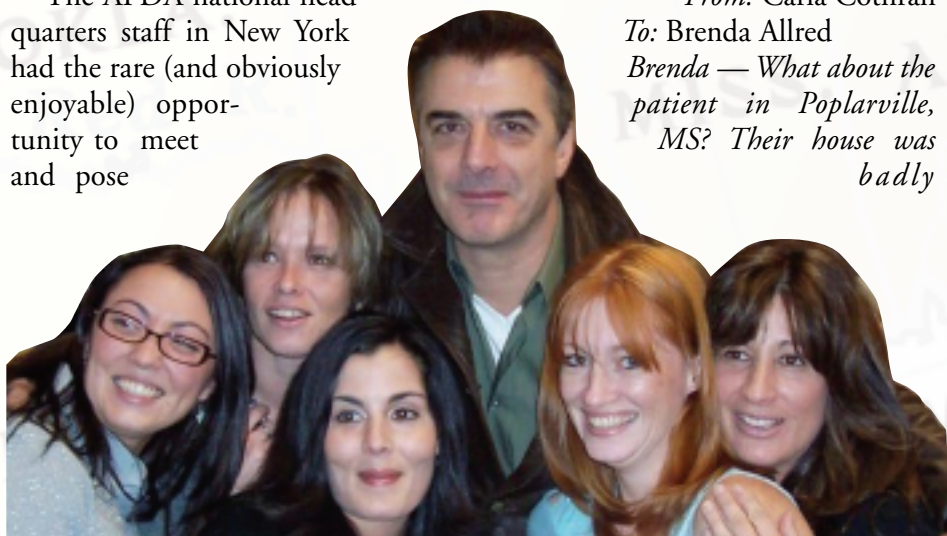


## In the Northeast

The “Cathi Thomas Award of Excellence and Merit,” will provide annual awards to neurology professionals including nurses, physical therapists, and caregivers in the New England region. Candidates will be chosen by the Boston University School of Medicine neurology department’s chairman and the director of the Movement Disorder Unit, who happens to be APDA’s I&R coordinator Cathi Thomas. Ernest Selig and his wife, Rae, recently created the award with a \$25,000 challenge gift to honor Cathi’s “many years of extraordinary service and exceptional dedication to the welfare of people with Parkinson’s disease.” Mr. Selig has been a PD patient for 10 years.

Brian Pastore, a Tuckahoe, NY, resident who has been a top APDA fundraiser on Long Island, turned his participation in a North Carolina triathlon into his own fund-raising event to honor his father, Al, a Parkinson’s patient in that state. Brian formed “Team Pastore” with t-shirts, brochures and a newsletter. APDA received \$1,500 from his efforts.

The APDA national headquarters staff in New York had the rare (and obviously enjoyable) opportunity to meet and pose



Law & Order star meets APDA cast.

with Chris Noth, star of TV’s “Law & Order, Criminal Intent.” The production company chose the office of Dr. Paul Maestroni, director of scientific & medical affairs, to shoot two scenes in an episode that aired in January. The lucky ladies are, left to right, Nancy Braun, Jill Goolic, Heather Duffy, Sharon Crimmins, and Emily Ciorciari.

## In the Gulf Coast Region

A series of e-mails among coordinators gives a glimpse of how APDA responded through its national network to assist Parkinson’s patients who were victims of the Hurricane Katrina disaster:

*From: Schaaf, Elizabeth (N. J.) To: Brenda Allred (Mississippi), Carla Cothran (Alabama), Maureen Cook, (Louisiana)*

*I have a church in NJ that wants to donate to a family with a person with PD affected by Hurricane Katrina. Do you have a PD family in great need....? My thoughts and prayers continue to be with you.*

*From: Carla Cothran To: Brenda Allred*  
*Brenda — What about the patient in Poplarville, MS? Their house was badly*

*damaged and her husband lost his shrimp boat.*

*From: Brenda Allred To: Carla Cothran*

*Yes... Elizabeth e-mailed me to say that Barbara Rignk, who runs the support group in Northern N.J., will be contacting the people in Mississippi to find out what their needs are and where they show, etc...*

*From: Carla Cothran To: Brenda Allred*

*I called and talked with the recipients... they were hesitant at first to accept anything from anybody because they felt there are so many others that are in worse shape. However, since I was looking specifically for Parkinson’s patients that were affected by Katrina, they said they would be glad to receive anything that is offered.*

## In the West



When Ava Crowder of Lubbock, Texas, passed away on Nov. 10, APDA lost more than a member of its board of trustees. Never a shrinking violet, and proud of it, Ava turned her diagnosis into a 26-year mission to make America aware of Parkinson’s disease including appearances on the “Phil Donahue Show,” “Good Morning America,” and before the U.S. Congress. We share her loss with her husband, Troy, who was a devoted caregiver, and her family. ■

## THE YEAR 2005 FRED SPRINGER AWARD

Dr. David Eidelberg, director of the Center for Neurosciences at the Feinstein Institute for Medical Research, North Shore-Long Island Jewish Health System, and Professor of Neurology and Neuroscience at New York University School of Medicine received the American Parkinson Disease Association's (APDA) 2005 Fred Springer Award.

Established in memory of Fred Springer, the APDA treasurer and past president for more than 20 years, the award consists of a plaque and a check for \$10,000 to a physician or scientist who has made a major contribution toward easing the burden and finding the cure for Parkinson's disease. The award was presented on Nov. 20, 2005 during the association's annual meeting at the Hilton Garden Hotel, Staten Island.

In 1996, Dr. Eidelberg received APDA's distinguished Dr. George C. Cotzias Fellowship and subsequently served for four years as a member of its Scientific Advisory Board, which reviews all research grant and fellowship applications and recommends for funding those it finds promising. APDA has contributed more than \$50 million to PD research and to patient support and has been a funding partner in every scientific breakthrough in this disease.■



*Dr. David Eidelberg updated the board on the latest areas of PD research after receiving the 2005 Fred Springer Award.*

## YOUR FUTURE DOESN'T STOP WITH DEATH

There is no law that a person must have a will, but there are laws in every state about what will become of their assets, if they don't.

States differ on their procedures, but generally the estate is allocated among surviving relatives. And, because the state cannot know how you would want your assets divided, it is usually equally. Friends and charities are part of any state's formula. In effect, your will contains your instructions on the disposition of your property as you want it.

People don't "bother" with wills for numerous reasons. Some feel that they don't need one because their estate is small. Some are intimidated about retaining a lawyer. And most mean to but just don't get around to it. None is a valid reason. A will is a responsibility, not a luxury.

**There Is No Estate Too Small.** If there is anything in your life — be it cash, property, bonds, a favorite piece of jewelry, stocks, an antique, or sports memorabilia — that you want to be sure will go to a specific person or organization, you need a will.

**Do You Need A Lawyer?** You need a lawyer to draw up your will as much as you need a physician if you have pneumonia. You may successfully treat your ailment, but would you take the chance? Laws governing estates are complex and vary from state to state, so it is highly recommended that an attorney draw up and file your will. Remember that

time saved is money saved when dealing with a lawyer, so prepare before your visit. Have an estimate of your estate — indebtedness (mortgages, loans, credit cards) as well assets. List all investments — stocks, bonds, pension plans, savings and checking accounts, IRAs, 401Ks, pensions and any other retirement plans, life insurance, as well as personal property including automobiles, property, furniture, jewelry, antiques, silver, and art. Don't forget any business interests. Know how you want your estate resolved, and who you want as the executor as well as an alternative. Your gifts to charities should also be considered, especially because they may be a tax benefit on your estate.

**You'll Get To It Sometime.** Remember Emily Dickinson's poem, "Because I could not stop for Death, he kindly stopped for me."

After the will is in effect, it is equally important to review and update it periodically. Family and friends change, expanding and decreasing. Children grow up, estates grow or decrease, executors may not be able serve any longer and/or you may have moved to another state with different probate laws. All are reasons to revisit your will's provisions.

If you have any questions about how to include APDA in your will, call Joel Gerstel, executive director, 1-800-223-2732.■



# Speech & Voice Problems in Parkinson's Disease

The ability to communicate is a key element in quality of life. Over 89 per cent of individuals with Parkinson's disease (PD) have a problem with their speech and voice. Reduced loudness, monotone, hoarse voice, and imprecise articulation are some of the common perceptual characteristics. These characteristics have been associated with bradykinesia and hypokinesia (slow and small movements) of the muscles involved in speech production. In addition, clinical observations suggest that individuals with PD are often not aware of their speech problem. When "soft speaking" individuals with PD are asked whether they speak too softly, they will often reply "No! My spouse complains all the time, but he/she needs a hearing aid!"

The spouse of the individual with PD may indeed need a hearing aid, but most often the individual with PD has a soft voice of which he or she may be unaware. This reduced awareness is one of the reasons speech treatment for individuals with PD has been so challenging over the years. Patients are able to improve their speech in the treatment room, but when they walk out of the door, the improved speech "disappears." This is frustrating for both the patient and the family.

Over the last 10 years, an effective speech treatment for individuals with PD has been developed and scientifically studied with support from the National Institutes of Health (NIH)-National Institute for Deafness and other Communication Disorders (NIDCD). The treatment is called the LSVT®, named after an individual with PD, Mrs. Lee Silverman who funded the original study. Individuals with PD who received LSVT improved their loudness, intonation, and voice quality and maintained these improvements up to two years after treatment. This is the first speech treatment for individuals with PD with published short and long-term efficacy data docu-

menting improved functional communication.

Recent research studies have documented improvements in the common problems of disordered articulation, facial expression, and swallowing in individuals with PD following LSVT. In addition, brain-imaging studies have also documented evidence of positive neural changes following LSVT.

LSVT focuses on improving vocal loudness by exercising the muscles of the



voice box (larynx) and speech mechanism. One single goal — "speak LOUD" — improves respiratory, laryngeal, and articulatory functions to maximize speech intelligibility.

Unlike traditional speech treatments, LSVT is administered in 16 sessions in one month (four individual sessions per week). This intensive mode of administration is consistent with theories of motor learning and skill acquisition, and appears essential to obtain optimum treatment results. In addition to stimulating the motor speech system, LSVT incorporates sensory awareness training. Initially, when individuals with PD are trained to improve loudness, they often will say, "I can't speak like this I feel like I am shouting."

This is a major hurdle to successful treatment. LSVT addresses this problem by helping individuals with PD recognize that their voice is too soft, convincing them that the louder voice is within normal limits, and making them comfortable with the new louder voice.

LSVT has been successfully administered to individuals in all stages of PD; however, individuals in Stages 1-3 of Hoehn & Yahr scale have had the greatest success. LSVT has been tried in individuals with many forms of PD, however, the largest data set was obtained in individuals with idiopathic PD. Addressing speech and voice disorders early in the course of Parkinson's disease is essential in order to maintain the best possible communication abilities for individuals with the disease. Communication is a key element in quality of life and can help individuals maintain confidence and a positive self-concept as they deal with the challenges of Parkinson's disease. We recommend beginning LSVT early so that you can "keep your voice alive!"

For optimum treatment results, it is essential that LSVT be delivered by an individual who is certified in this method.

Only speech clinicians who have attended an LSVT training and certification workshop can use the name LSVT. These clinicians have additional knowledge about PD and in addition, LSVT certified clinicians receive continued updates as research advances.

The LSVT certification mark is held by the LSVT Foundation, a non-for-profit (501 C3) organization. The Foundation, besides holding workshops to train speech clinicians, maintains a database of certified clinicians across the U.S. and abroad.

For additional information about LSVT, a list of published articles, and to locate LSVT certified clinicians in your area call: 1-888-606-5788 (LSVT), or visit the LSVT Web site: [www.LSVT.org](http://www.LSVT.org). ■

*Abstracted from "Speech and Voice Problems, Etc." published in Fall 2005 Parkinson News & Views Newsletter of the APDA Chapter in Tucson, AZ.*

## TRAVELING & YOUR MEDS

If you are planning a trip, especially if you will be traveling abroad, here are a number of steps you can take to make your travel as hassle-free and enjoyable as possible.

**1) Make sure you have copies of all your prescriptions, including the generic name of each medication.** The generic name is important; there may be medications whose names sound similar to the brand name of your drug, but that are completely different from it. If you lose your medication, a local pharmacist should be able to help you if you can show a copy of the prescription and the generic name of the drug.

**2) Carry a note from your physician that includes office contact information.** This is especially important if any of your medications is a controlled substance (e.g., Vicodin, Ambien, Hydromorphone), or given by injection (e.g., insulin).

**3) Keep all medications in their original labeled containers.** This includes over-the-counter products like aspirin, vitamins, and herbal products.

**4) Keep all your medications in your carry-on luggage.** This will enable you to access them if there should be a delay in the luggage delivery or if your checked luggage is lost.

Some prescription medications are considered over-the-counter in other countries, and will be relatively easy to replace. Others may not be widely available, and may be more difficult to replace. If you will be traveling outside the United States, it might be useful to check on the Internet to see if your medications are available in countries you will be visiting and their trade names.

With your regular medications safely at hand, and back-up plans to replace them in case of emergency, you'll be able to relax and enjoy your holidays — wherever you may be celebrating! ■

*Adapted from "Ask the Pharmacist," in The Parkinson, October/November 2005, San Diego APDA I&R Center Newsletter.*

## Parkinson's Disease Medications

*continued from page 1*

ipate its availability within the next few months. *Advantage:* NOT A PILL!!! Once a day application.

"Doc, my cousin has an insulin pump for his diabetes; and I have a son with multiple sclerosis who has a Baclofen® pump; when are they going to have a pump for dopamine?"

The answer: "I do not know" But, it makes perfect sense, doesn't it? To have a continuous supply of dopamine being pumped into your body, at just the right rate...

The good news is that they are currently doing a study with a **pump** that continuously pumps carbidopa/levodopa into the patient...I will keep you apprised of the results.

These are in a nutshell the current "medication delivery" forms.

There are a few basic principles that all people who have, or work with, Parkinson's disease must understand.

**First:** this is a progressive disease. While there is promising research going on, no medication to date stops the brain cells from dying. This results in continued loss of dopamine in the brain. And the longer you have Parkinson's the less dopamine your brain produces. The less dopamine your brain produces, the harder it is to replace with medication.

**Second:** the brain is designed to have a fairly constant level of dopamine available in order for it and your body to function properly. Too much dopamine causes too much movement; too little dopamine causes lack of movement and the appearance of tremor. It is also important to understand that too much fluctuation of the dopamine levels "trains" the brain to be more "picky" and "narrow minded" about what is too little, enough, and too much dopamine. And of course, as the brain produces less and less dopamine the levels become more and more dependent upon the pills that you take.

**Third:** any time you take a medication, it has to be absorbed into the blood stream, at which point the body starts to break it down and get rid of it. Because of this, the amount of medication in the

blood rises from a low (ineffective) level, to an effective level, then to a high (too much) level, then gradually goes back down to an ineffective level. Different medications last different lengths of time in the body; and it may take 2-5 days for a medication to reach a stable (constant) level/balance in the body...and then only if you take the medication reliably.

If you understand these three principles, you can begin to see why it is that over time doctors increase the number and dose of your medications; why the doctors may tell you to take your medication more frequently; and why doctors want you to take your medications very reliably. Let me try to explain.

Ideally, you should try to keep your dopamine levels "constant". Thus, it would be good to constantly take the medication (translation: take the medication by pump or patch); but because most of our medications are pills it means you would have to take pills every hour. This is not feasible; so you should take a pill that is long lasting. These pills include the dopamine agonists (Pergolide, Pramipexole, Ropinirole, and Bromocriptine). While these pills help, and early on they may be sufficient, they tend to be fairly weak. Thus, over time, other pills that replace dopamine need to be added (because of continued loss of brain cells that produce dopamine).

Often a continuous release form of Sinemet (Sinemet CR) is used to raise the overall level of dopamine, trying to keep the level from fluctuating. The immediate release form of Sinemet may also be used; but because it doesn't last as long, the fluctuations of dopamine levels can be quite dramatic. These lead to the long term side effects known as dyskinesias, and sudden "wearing off" (translation: the brain has now been trained to be too picky...). To help avoid these side effects, more frequent dosing is required; sometimes as often as every three hours!

In order to make the Sinemet last longer (translation: reduce fluctuations of dopamine levels), Comtan is often added. This makes it so the body cannot break down the Sinemet as rapidly, thus keeping

the level of dopamine more stable. Selegiline and rasagiline also make the dopamine last longer, but mostly once the dopamine is in the brain, not while it is in the rest of the body. ■

*Abstracted from the John Steffens, MD articles "Pills, Patches and Pumps" and "The Purpose Behind the Pill" published in The Summer and in the Winter 2005 Parkinson's News, the APDA Salt Lake City, UT I&R Center Newsletter.*

## To Drive or Not to Drive?

Most of the people equate the ability to drive a car with being independent, being able to socialize, and have self-esteem. Individuals who have Parkinson's disease (PD) are no different. No wonder questions about this activity raise mixed emotions, hesitancy, and even indecision for individuals who reach the threshold of this important choice. Some wonder if they will recognize when the time comes to give up something so important to our mobile society. It is difficult to make a rational, objective decision when one may be emotionally influenced by personal desire, social stigma, and cultural influences.



can one note a ball rolling into the street at the same time a light is turning red and a person on a bicycle enters the intersection?

### 4. *Motor Deficits*—

Bradykinesia can slow reaction time. Tremor and rigidity can interfere with coordination of movements.

Ms. Hamelburg sums up her information with the idea that a driver is only as good as his/her worst moment.

Dr. Dwight McGoon, a Mayo Clinic surgeon with PD, offers several additional thoughts from personal experience in his book, *The Parkinson's Handbook*. He states that he drives only during the medicated part of his day, and usually defers driving to unimpaired drivers if they are along.

He feels sleepiness from medications can be a problem and he tries to make sure he had a nap prior to driving and that he does not drive immediately after eating in order to avoid sleepiness. He advises seeking the advice of friends and family who can objectively observe a person's delayed reactions, close calls, displays of poor judgment, and other things that may be easy for an individual with PD to miss. He feels that, as a general rule, if doubt exists it is better not to drive.

Each person with PD needs to make an honest assessment of his/her ability to drive safely as PD progresses. Creativity may be required to develop solutions to the problems created by giving up driving, and some support groups have used this as a topic for discussion. There is much to be learned from people in the same boat. ■

## A NEW WAY TO HELP PEOPLE GET PRESCRIPTION MEDICINES

Millions of people across the country have difficulty affording health care, including prescription medicines. Many people lack health insurance or simply do not have the money to pay for the medicines they need.

A coalition of biopharmaceutical companies, doctors, health care providers, patient advocacy organizations and community groups have formed the Partnership for Prescription Assistance — the largest ever private-sector nationwide program to help qualified patients to get the medicine they need.

This patient assistance program available through the Partnership for Prescription Assistance offers prescription medicines to treat a broad range of illnesses and conditions including Parkinson's disease.

The American Parkinson Disease Association (APDA) is a leader in this groundbreaking effort. Helping the needy is a top priority for APDA and we are pleased to be a partner in this effort to bring medicines to those in need.

By calling 1-888-4PPA-NOW (1-888-477-2669), patients can learn whether they may be eligible for one or more assistance programs. Patients can also visit the program's user-friendly Web site, [www.pparx.org](http://www.pparx.org), which will guide them through the application process. ■





# Information on Parkinson's Disease

*Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling the toll-free number 1-800-223-2732 or Fax 1-718-981-4399.*

## EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**  
4-page brochure (English, Chinese, Spanish)
2. **Parkinson's Disease Handbook**  
Symptoms, causes, treatment; 40-page booklet (English, German, Italian, Portuguese, Spanish, Russian)
3. **PD "n" Me — Coping with Parkinson's disease;**  
70-page booklet (English)
4. **Be Active — A suggested exercise program for people with Parkinson's disease;** 25-page booklet (English, German, Italian)
5. **Be Independent — Equipment and suggestions for daily living activities;** 32-page booklet (English, German, Italian, Spanish)
6. **Speaking Effectively — Speech and swallowing problems in Parkinson's disease,** 34-page booklet (English, Japanese)
7. **Good Nutrition**  
20-page booklet (English), new edition
8. **Young Parkinson's Handbook**  
78-page booklet (English)
9. **How to Start a Parkinson's Disease Support Group**  
24-page booklet (English, Italian)
10. **Aquatic Exercise for Parkinson's Disease**  
20-page booklet for patients and their families (English)
11. **Next Step After your Diagnosis — Finding Information and Support**  
23-page booklet (English)
12. **My Mommy Has PD... But It's Okay!**  
20-page booklet for young children.

## EDUCATIONAL SUPPLEMENTS

Caring for the Caregiver: Body, Mind and Spirit; The Family Unit; The Fine Art of "Recreating & Socialization" with PD; Medical Management of PD; Vision Problems and PD; Mirapex® in the Treatment of PD; Fatigue in Parkinson's Disease, (December 2005), and others.

## DVD

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

Created by the Washington State Chapter of APDA especially for newly diagnosed Parkinson's patients and their loved ones. Leading experts explain what PD is and how it is treated, how to deal with symptoms of the disease and some of the medications' side-effects and how to keep a positive outlook in dealing with it.

## APDA WORLDWIDE WEB SITE

[www.apdaparkinson.org](http://www.apdaparkinson.org) for PD I&R Centers, Chapters, Support Groups, Education and Information Material, Meeting Dates, Publications, Medical Abstracts, Clinical Trials, etc.

## WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

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

## AFTER YOUR DIAGNOSIS

The Federal Agency for Health-care and Quality has published a free booklet *Next Steps After Your Diagnosis: Finding Information and Support* to help newly diagnosed patients to understand and obtain medical information concerning their disease.

The five sections of the booklet are intended to help individuals cope with the diagnosis, make decisions and get on with life. It also includes a list of 10 important questions to ask the doctor.

Additional information on medical research, clinical trials, and health care is also provided.

The booklet can be obtained free of charge via the Internet at [www.ahrq.gov/consumer](http://www.ahrq.gov/consumer), or by calling the toll free number 800 358-9295 or APDA. ■

## STEPS — A NEW CLINICAL STUDY

STEPS is a clinical research study to evaluate a new treatment being developed for Parkinson's disease. To participate in the study patients must be between the ages of 30 and 70, have had Parkinson's disease for at least five years and currently experience insufficient control of the symptoms even with optimal oral medical treatment.

**If you are interested in participating in this study and would like more information, call 1-866-STEPS-03 (1-866-783-7703). ■**

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