

# The American Parkinson Disease Association

S U M M E R 2 0 0 4 N E W S L E T T E R

## The American Parkinson Disease Association

A Quarterly Newsletter ©2004  
by The American Parkinson  
Disease Association, Inc.

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## SLEEP DISTURBANCES IN PARKINSON'S DISEASE

*Rochelle Zozulla, Ph.D., Clinical Director, Comprehensive Sleep Disorders Center,  
Robert Wood Johnson University Hospital, New Brunswick, NJ*

**I**t has become increasingly apparent that movement disorders are present during sleep, and they may cause, or be associated with, a variety of sleep disturbances. Additional problems arise because treatment of the movement disorders may cause disturbed sleep. Sleep difficulties have been found to be common in patients with Parkinson's disease (PD) with many patients complaining of difficulty getting to sleep, disruption in sleep, inadequate time spent asleep, daytime sleepiness, disturbing dreams and nocturnal vocalizations.

A survey of 220 PD patients reported that 32 per cent of them complained of excessive nocturia (need to void), inability to change positions in bed during the night or upon awakening, inability to get out of bed unaided, leg jerks and cramps, dystonic spasms of the limbs or face, and back pain.

Some of the sleep-related complaints, such as difficulty initiating and maintaining sleep, may be associated with the age of the patients. Sleep quality tends to decline even in relatively healthy older individuals. In addition, sleep disruption may be associated with changes in mental status, which may accompany the later stages of PD.

In addition, patients with PD are prone to depression. Depression in itself can cause changes in the sleep architecture, including early-morning awakening and early onset of REM (rapid eye movement) sleep. Depression may also increase the response to other PD symptoms, such as pain, and increase their impact on sleep.

PD patients are also at risk for the

development of primary sleep disorders such as sleep-disordered breathing and parasomnias (unusual behaviors that occur out of sleep or during sleep-wake transition). This may be due to changes in central nervous system functioning and changes in the control of upper-airway musculature that occur in the evolution of PD. According to Schenk and colleagues, the parasomnia known as REM-sleep behavior disorder (physically acting out one's dream) can occur years before the onset of actual daytime PD symptoms.

Sleep studies conducted in the laboratory have identified that poor sleep is common in PD, usually worsening with the severity of the disease.

There seems to be no single cause for disturbed sleep.

- Studies have shown the following changes can take place:
- Persistent tremor (particularly during lighter stages of sleep and during sleep-wake transition), dyskinesias, or dystonia.
- Drug-induced motor restlessness (akathisia) and symptoms occurring in the evening and interfere with initiating sleeping.
- Awakening from sleep with difficulty changing position or getting out of bed.
- Abnormal movements such as REM — sleep behavior disorder, REM sleep motor



*Continued on Page 3*

## INDEPENDENT LIVING SUGGESTIONS

- Carry a day's supply of medication with you at all times. Have your partner carry an extra supply of your medications. This is important, as you may drop a pill, forget your pill case or need an extra dose.
- Avoid being seated in a booth in a restaurant. Request a chair with arms, if possible.
- Avoid deep-seated chairs — they are difficult to get out of. Also avoid a chair with a footstool in front of it. The stool may get in the way and cause you to fall.
- Buy a length of satin to put across the width of your bed. It is less expensive and easier to find than a sheet.
- A cordless phone can be carried in a bag, which can be hung from a walker. This eliminates the need to hurry to answer the phone.
- Exercise your mind as well as your limbs. Do crossword puzzles, and cryptograms. Read and expand your mind.
- A spoon works better than a fork for food that will roll around, such as peas.
- Eating often takes a long time. An insulated dish will keep the food warm and/or cold. ■

*Adapted from Parkinson's News, APDA  
Salt Lake City, UT*

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



Dear Reader,

One of my most enjoyable functions as president of the American Parkinson Disease Association is participating in the annual meeting of our Scientific Advisory Board, at which time applications for research grants and fellowships are voted upon, and presentations by each of our advance centers for research are made. Even before the meeting begins, each member of this distinguished panel has given hours of time reading and evaluating each application, but when they are all assembled in one room and interacting with their fellow scientists, the whole becomes even greater than the sum of its parts. (See pages 8-9 to learn more about the process of selecting grant recipients and a list of the 2004 recipients.)

This year APDA received a record number of applications, an indication of the growing dedication to research in our area, and after the evaluations were made, more than \$2.5 million was committed to support promising new research and to continue support of previously selected goals.

Another very positive research milestone was reached in May, when New Jersey Governor James McGreevey signed documents creating the nation's first state-funded institute dedicated to stem-cell research — The Stem Cell Institute of New Jersey. The institute, when opened, will be jointly operated by Rutgers University and the University of Medicine and Dentistry of New Jersey, one of seven APDA Centers for Advanced Research across the country. The state will provide \$6.5 million to initiate the public-private venture, ensuring research with the potential of helping not only Parkinson's patients but also millions of others suffering from other chronic diseases.

I was also delighted to be invited to a local elementary school graduation recently to accept a \$100 check from a student group. A student panel charged to research worthy recipients selected only three not-for-profit organizations to receive these funds and APDA was one. While the amount is small in comparison to the millions of dollars needed for sophisticated research, the fact that APDA was selected shows that awareness of the disease and its impact are becoming known to all ages.

Those of us who are involved in finding a cure and certainly more so, those afflicted with PD and their loved ones, know how painfully slow this methodical and costly processes is. Yet, each grant, each governmental initiative, each young person's effort to help accelerates the ultimate achievement that much more.

The culmination of all these small steps will ultimately lead us to our goal.

Sincerely,

A handwritten signature in black ink, appearing to read 'Vincent N. Gattullo'. The signature is stylized with a large, looped 'V' and a cursive 'G'.

Vincent N. Gattullo  
President

# FREE OR DISCOUNTED MEDICATIONS FOR PARKINSON'S DISEASE PATIENTS

*Michele Popadynec, RN*

Pharmaceutical companies offer assistance to individuals meeting their income criteria and not having insurance coverage. If the income is over the required amount medication can be obtained at a discounted price anywhere from 20 per cent to 40 per cent depending on the drug.

Following is a list of medications used in Parkinson's disease and telephone numbers to be used to contact the pharmaceutical company:

MEDICATION	PHARMACEUTICAL COMPANY	PHONE
Comtan Parlodel Stalevo	Novartis	1 800 277-2254 option 2
Mirapex	Boehringer Ingelheim	1 800 556-8317
	Pfizer	1 800 459-4156
Permax	Amarin	1 866 262-7468
Requip	GlaxoSmithKline	1 866 728-4368
Sinemet	BristolMyersSquibb	1 800 736-0003
Symmetrel	Endo Laboratories	1 800 319-4032
Tasmar	Roche Laboratories	1 800 285-4484

Other sources for obtaining applications for free or discounted medications are:

RESOURCE	PHONE	INTERNET	ADDRESS
TogetherRx	800 865-7211	<a href="http://www.TogetherRx.com">www.TogetherRx.com</a>	PO Box 52158 Phoenix, AZ 85072
Free Medication Program	646 205-8000	<a href="http://www.freemedicationprogram.com">www.freemedicationprogram.com</a>	1632 York Ave. N.Y., NY 10028
Medicine Bridge	877 667-6337	<a href="http://www.medicinebridge.com">www.medicinebridge.com</a>	PO Box 202318 Austin, TX 78720
Rx Solutions	800 562-6223	<a href="http://www.RxSolutions.com">www.RxSolutions.com</a>	PO Box 509075 San Diego, CA 92150
Peoples Prescription Plan	800 667-6914	<a href="http://www.peoplesrxcard.com">www.peoplesrxcard.com</a>	
RxHope	908 850-8004	<a href="http://www.Rxhope.com">www.Rxhope.com</a>	254 Mountain Ave. Building B Suite 200 Hackettstown, NJ 07840

## EDUCATION KIT FOR PEOPLE WITH PARKINSON'S DISEASE

Novartis Pharmaceuticals Corporation has announced the availability of a new, free of charge information and resource kit designed to help educate people living with Parkinson's disease and their families, friends and caregivers. "Managing Parkinson's Disease" was developed in consultation with the American Parkinson Disease Association (APDA), and other non-for-profit Parkinson associations, with full sponsorship from Novartis Pharmaceuticals Corporation as part of its Stalevo Educational Programs initiative. To obtain a free kit, you can call toll-free 1-866-STEP-Kit (1-866-783-7548), or visit [www.stepkit.net](http://www.stepkit.net). ■

## Sleep Disturbances

*Continued from Page 1*

dysfunction (increased muscle tone during REM sleep), periodic limb movements during sleep, or REM — onset eye blinking may disrupt sleep.

■ Sleep disordered breathing, including sleep apnea and upper airway resistance syndrome.

■ Loss of sleep-wake regulation due to progressive central nervous system degeneration. This can lead to poor sleep maintenance or "sundowning" behavior (onset of confusion and agitation during the nocturnal hours).

Treatment of PD has not been found to improve sleep in all patients. In some cases, drug therapy for PD (L-dopa or dopamine agonists) may alleviate abnormal movements during sleep. In other cases, under-medicated PD patients may improve sleep with the increase in the medication. Over a period of time, the patients may find that they are trying to balance their need for medication to maintain daytime functioning. Slight adjustments in the timing, dosage and type of medication may alleviate the problems.

Separate treatment with benzodiazepine drugs may be helpful for patients with REM sleep behavior disorder or periodic limb movement disorder. In addition, treatment of sleep apnea (either with continuous positive or bilevel airway pressure therapy) can be beneficial in patients with this primary sleep disorder.

It is important for PD patients to recognize the potential impact of the disease on sleep and to discuss any sleep-related problems with their physician(s). Since several of the sleep disturbances may coexist in an individual with PD, it may be helpful to seek the expertise of a sleep-disorder specialist to assess the underlying nature and severity of their suspected sleep disorder (e.g., sleep apnea, REM — sleep behavior disorder), and to work with the doctor to establish a comprehensive treatment plan. ■



# Questions & Answers

Enrico Fazzini, D.O., Ph.D

Assoc. Prof. Neurology New York University, New York, N.Y.,

University of Nevada, Las Vegas, NV,

N.Y. Institute of Technology, Old Westbury, N.Y.

**Q:** Are all of the medications for PD administered orally?

**A:** As of this writing, all of the medications used to treat PD are taken by mouth. However, a few weeks ago, a medication called apomorphine was made available, which is given as an injection under the skin. This medication is a synthetic dopamine, like Permax, Parlodel, Mirapex and Requip. It differs from these other medications in that apomorphine produces a beneficial effect within 3 to 5 minutes, although the effect only lasts 1–1 1/2 hours. It will be used as a rescue from a severe “off” state, which can occasionally occur in patients who fluctuate in response to their normal daily schedule of medications. In addition, a skin patch using Rotigotine is in the last stages of a large trial and may be available in one or two years. This dopamine agonist patch provides a continuous release of anti-PD medication and therefore is very useful in preventing “on”/“off” fluctuations.

**Q:** What is the scoop on Permax and heart-valve abnormalities?

**A:** Permax (pergolide) is a dopamine agonist derived from ergotamine. It is known that ergot-derived medications may rarely produce fluid in the lungs and heart valve dysfunction. The issue has received more attention after a Mayo Clinic report last year of three patients with an unusual heart-valve abnormality while taking Permax. In addition, at the recent American Academy of Neurology meeting in San Francisco, a study was presented in which 89 per cent of 46 patients taking Permax were found to have some degree of heart-valve problems when compared to age-matched controls. This study was not scientifically conducted, as much larger numbers of patients should be screened before and after taking Permax and these patients should be compared to PD patients on other dopamine agonists and without dopamine agonists. However, it would be prudent not to treat PD patients with pre-existing heart disease with Permax, and patients on Permax should be monitored by auscultation of the heart on examination and echocardiogram if any signs of cardiac dysfunction become present. Permax although being derived from ergotamine, has more physical benefit and less hallucination potential than Requip and Mirapex in many patients and is particularly useful in older patients with dementia. I have personally never seen any cardiac problem associated with Permax use in any of my patients in more than 20 years of clinical practice.

**Q:** Any new information on trials using GDNF?

**A:** A group from England reported two-year follow-up on patients with PD who have had an infusion of GDNF into the posterior putamen (a part of the basal ganglia which is lacking dopamine in patients with PD). They found a 41 per cent improvement in the scale (UPDRS) used to measure PD. The improvement was associated with a 23 per cent increase in the uptake of dopamine into this brain area, as measured by PET scans. A word of caution: the mechanism is postulated to be sprouting of remaining neurons. If the neurons are diseased and they are stressed further by producing and transporting more dopamine than they normally do, it could eventually lead to a worsening of the PD over time. This could be likened to placing more homes and businesses on the line of an existing and poorly managed power plant. The power plant may be able to ramp up electricity production initially, but the machinery may eventually break down sooner than if it had been left alone with a smaller need for power output. In addition, I am always afraid of the possibility of neoplasm with the use of trophic factors. Nevertheless, this may at some point lead to a new treatment of patients with PD. ■

## The "Gift" of PD Makes Carol Lenz A Model Ms. New York State

If she could, Carol Lenz would hold the whole world in her arms and give it a big hug.

On Nov. 14, 2004, the Bronx-born former school teacher will have made her way from a first-grade classroom on Manhattan's lower East Side to the stage of the Las Vegas Imperial Palace, where she will be New York State's representative in the Ms. Senior America Pageant, with one major stop — being diagnosed with Parkinson's disease 10 years ago.

The 60-year-old wife of Bellport, NY, insurance businessman Gordon Lenz says she considers PD, "a gift. It slowed me down and makes me cherish every moment."

Carol discovered "something was wrong," while blow-drying her hair one day. "I couldn't hold the dryer still enough to dry my hair," she remembers. She admits to being "taken aback and surprised," at the diagnosis, "but not frightened. At first you try to hide it, but everyone knows."

But no one who knows this self-proclaimed "cockeyed optimist" would be surprised at her reaction because

historically she has turned adversity into opportunity. When her first husband, a physician, was in military service and assigned to the federal penitentiary health system at

Leavenworth, Carol gathered up their 4-week-old baby, Jennifer, moved with him to Kansas, and immediately opened a much-needed nursery school. Then she joined a theatre group that performed in the prison.

When the fatigue she often feels ended her regular tennis schedule, she added a book club to the group's regular activities.

So, when her assistant of nine years, Diane Eddings, read a notice that the Ms. New York State competition of the Ms. Senior America pageant was being held in Long Island's Suffolk County, Carol said, "Why not?" She had performed on stage, still played her guitar, and had sung every night with her mother, who had a severe heart condition and died at age 50.

Carol and Diane worked for six months, and on April 18, with a wheelchair in the car ("just in case"), Parkinsonian Carol Lenz wowed the audience with her grace, charm and rendition of "Getting to Know You" from "The King and I"

and walked away with the title of Ms. New York State and the crown, which she doesn't care to remove too often and even wears during her neurology visits!

Carol says she is the product of a loving home and that love has influenced her whole life. Her undergraduate and graduate studies at New York University were in early-childhood education and guidance to prepare her for her career teaching special education and underprivileged children. She concluded her career with 11 years as K-12 guidance counselor for the Eastport (NY) School District on Long Island.

"I could have felt defeated, but I can't. I'm a lot like Nelly Forbush in "South Pacific." I look at life

joyfully and try to greet the world with a smile." ■

*Carol considers her PD a gift that has slowed her down and makes her cherish every moment.*





## In the East

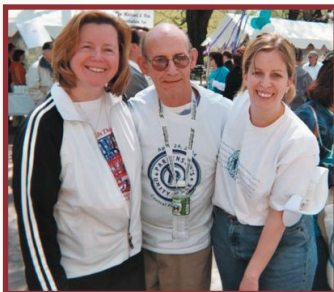
April was hardly the cruelest month for two APDA New England groups: The Rhode Island Chapter launched the month with a health fair at Newport Hospital, was featured on the NBC-TV affiliate's Coffee Cup Salute, a popular awareness promotion in the Granite State, and on the 17th, Dr. Patricia Nolan, the state director of health, joined in proclaiming Parkinson's Disease Awareness Month. Citations from the state Senate, House of Representatives and Governor's Office were part of the Chapter's "Living Healthy with Parkinson's" workshop. And that was only the middle of the month.

Following were a senior center presentation, participation in a Senior Living expo, and a 45-person team participation in the Annual Unity Walk in NYC's Central Park, raising \$8,000 for research. Massachusetts's annual Winchester Symposium featured Scientific Advisory Board members Drs. David Standaert of Massachusetts General Hospital and Marie Saint — Hilaire, director of the Boston I&R Center. Coming up are the New England Regional DP Symposium, Oct. 12, and the ninth annual Massachusetts APDA Putt for Parkinson's Disease, Aug. 30.

Those seeking the good life should have stopped by Erie, Pa. last month where the I&R Center partnered with Harmot Medical Center and HealthSouth Rehabilitation Hospital for the "Living Well Workshop." Speakers addressed coping and car-

ing; demonstrations included chair exercises, massage and mini-manicures were offered along with giveaways, new product samples, services and light refreshments — all free.

Everyone knows about the ol' rat race, but they're still talking about the Great Gerbil Race in Pittsburgh. I&R Center coordinator Barb Baser reports that lots of fun and information were the order of the evening, including Dr. Susan Baser's talk about new PD medications, Jugglin' Joe Wagner, and karaoke — all leading up to the race won by "Scratchy" given to a single mom to replace her daughter's pet gerbil, which recently had died. On Sept. 15, the popular Three Rivers Seminar Cruise on the riverboat Majestic will feature updates on PD medications, treatments and surgical alternatives. Jugglin' Joe Wagner will return.



*Staten Island I&R Center coordinator Diane Lee and New Jersey Chapter president Bill Lear and I&R Coordinator Elizabeth Schaaf share a moment during the eighth annual Unity Walk in New York City's Central Park.*

## In the South

Kathy Edwards notes that a lot of work resulted in a lot of fun and more than \$32,000 for PD research in Atlanta during the annual 5K Run. Hundreds of runners, walkers, riders and pets (see photo) teamed up with Mother Nature for a beautiful day.

In South Florida, the I&R Center conducted its "Quality of Life Caregiver Education Series," an intense four-day, 16-hour program in May. Topics included medical and surgical treatment, pharmacology, nutrition, elder law,



*They're off! Pittsburgh's great gerbil race seems like a sure thing from the start.*

financial planning, care management, rehabilitation, home health, adaptive equipment, senior centers and retirement facilities.

## In the Midwest

The St. Louis Chapter's annual PD patient and family Spring Dance in April included music, a barbershop quartet and a box dinner. The May "2004 Nat Dubman Memorial Golf Classic" drew a record 108 golfers — and for the first time "we had beautiful weather!" Proceeds benefit respite care and day care for Parkinsonians.

## In the Northwest

St. Alphonsus Regional Medical Center was a magnet for those seeking information about PD in Idaho. Approximately 70 attended the Parkinson's Conference, with 15 arriving from more than 250 miles away. Topics included caregiver support, nutrition, voice training, Chi Gung and therapeutic massage techniques.

## In the West

Sometimes raising money can be as pleasurable as it is rewarding. Take the Greater Los Angeles Chapter's

*continued on page 7*



*Friends, families, babies and pets joined to make the Atlanta Chapter walk a success.*



annual Walk-A-Thon where more than 250 people, young and old, some in wheelchairs or with walkers — many with their children, grandchildren and pets — were all walking with a purpose. Mayor James Hahn gave a warm welcome and expressed his gratitude to APDA for its work. The event made \$17,000, and funds are still coming in.

## In the Southwest

Cool, rainy weather not withstanding, 75 brave men, women, boys and girls endured the elements to participate in the Annual APDA/Coach Tom Chandler Memorial 5K Run and Mile Walk on the Texas A&M University campus. Mrs. Willowdean Chandler, widow of the Aggie's late baseball coach, was the official starter. Ben White reports that the Brazos Valley Chapter has added two new support groups in Bryan/College Station and Huntsville, a new group in Brenham and a Young Onset group in Bryan/College Station.



Chocoholics of the world eat your heart out! You missed the West Texas Parkinsonism Society Chapter's Wine and Chocolate

Fantasia. Lubbock I&R coordinator Jo Bidwell laments that there were only 300 tickets available. What chocoholic wouldn't want to sample chocolate tortillas, fortune cookies and pralines, plus chocolate mousse-tini, and triple layer chocolate cake with chocolate ganache and berries? Well, there's always next year!

### Galas Galore

Two galas benefiting APDA highlighted the spring social season in Dallas, Tx., and Martinsville, NJ. The latter, "An Evening of Musical Magic," celebrated the agreement between APDA and Young Onset Parkinson's Association (YOPA).

Harry Carson, nine-time Pro-Bowl linebacker for the Super Bowl Champion New York Giants, hosted the YOPA-APDA gala featuring music of Broadway, nightclubs and opera by Christiana Amonson, David Robinson and event chairwoman Gina Reilly. West coast director Sharin Klisser co-chaired.

National board director J. Patrick



Former New York Giant linebacker Harry Carson and event chairwoman Gina Reilly hosting the YOPA-APDA gala.

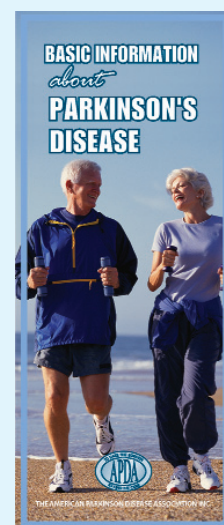
Wagner, who attended the Dallas event with his wife T.J., reported about the former: "The Greer Garson — E.E. Fogelson Humanitarian Award was presented to the William Slicker Family of Dallas in recognition

of the family's establishment of the Anne C. Slicker Early Parkinson Detection Center at Presbyterian Hospital of Dallas. This prestigious APDA award was coordinated by Fred Greene of the Dallas Chapter and is presented at the annual Greer Garson Gala, which benefits the APDA Information & Referral Center at the hospital, and enables the center to provide free patient services and to support research at the Fogelson Neuroscience Center. ■

### Two New APDA Information Sources Available

APDA has launched two new information vehicles:

- PD News & Updates is a new menu option on the APDA Web site, [www.apdaparkinson.org](http://www.apdaparkinson.org). PD News & Updates provides the latest information on major aspects of PD treatment and research findings. The materials are available through an exclusive agreement between APDA and WE MOVE, a science-based, not-for-profit organization focusing solely on movement disorders and related conditions. The option has three pages and, when completed by October, will include Patient Information and Physician Information components. More information about WE MOVE is available at [www.wemove.org](http://www.wemove.org).
- Basic Information about Parkinson's Disease is a redesigned brochure giving fundamental information about Parkinson's disease, APDA, and guidelines for supporting APDA's work. The four-color flyer includes a tear-off return order form for free educational materials. ■



APDA's newest informational brochure encourages activity and positive attitudes.

## APDA Awards \$2.5 Million to Research

When APDA funds more than \$2 million in research grants and fellowships to research institutions and individual scientists each year, the announcement brings with it a renewed hope that among the projects will be the cure for Parkinson's disease. Few people, however, realize how much time and effort an extraordinary cadre of physicians, scientists, and researchers had contributed well before the announcement is made.

"When people entrust their money to APDA for research, they put their trust in us to put it to the best use toward finding a cure, and whether it is \$5 or \$500,000, we take that commitment very seriously," says APDA President Vincent N. Gattullo. "I think that our Scientific Advisory Board (SAB), composed of 12 of the nation's most outstanding scientists in the field of Parkinson's disease, which reviews and evaluates every study proposal and makes recommendations for all research funding, is definitive proof of that commitment. It is especially noteworthy that this distinguished

group contributes its time and knowledge each year."

The process begins months before the SAB meets (this year on May 7-8), when the year's awards and application deadline are made public in scientific publications and posted on the APDA Web site. To be eligible, a candidate must complete an application form and provide a description of the proposed research, a statement of how the research is related to Parkinson's disease, and his/her National Institutes of Health-Biosketch. One original and 20 copies must be submitted.

As applications arrive at APDA's national office in New York, scientific and medical affairs director Dr. Paul Maestrone and his staff sort and catalog each before sending them to the SAB members. This year a record 101 study proposals in genetics, cell biology, biochemistry and behavioral studies were received.

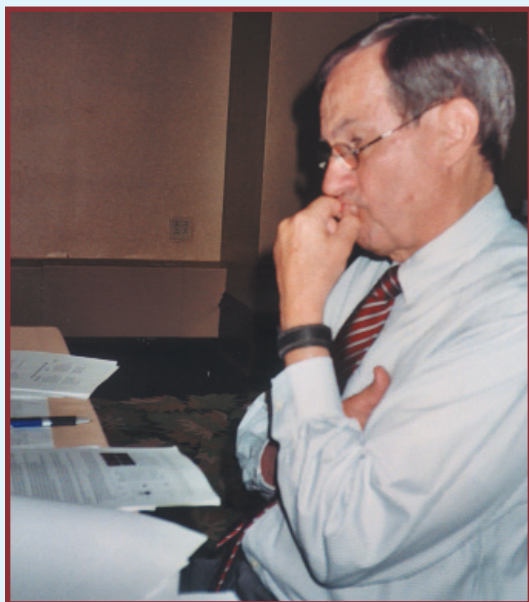
All applications are reviewed by the SAB chairman, G. Fredrick Wooten, MD, chairman of neurology at the

University of Virginia's Health Sciences Center in Charlottesville, who assigns a primary and secondary evaluator for each.

When the board convenes, each application is presented by its primary reader, given an evaluation by its assigned secondary reader, discussed by the entire board (which has read all the applications) and given a weighted value by secret ballot. The votes are compiled and the application given its average value. Any board member who is a nominee, or affiliated with the institution from which the application is originated, is excused from discussion and voting. The highest-ranking applications in each category will be funded.

It takes two long and grueling days of discussion, evaluation and analysis before the awards are finalized, but, when completed, everyone who has participated feels a rush of accomplishment and rekindled hope that he/she has perhaps played a part in finding a cure for Parkinson's disease. ■

### APDA 2004 Scientific Advisory Board



*Dr. Wooten considers an application's merit.*



*Front row (left to right): G. Frederick Wooten, MD, chairman; Vincent N. Gattullo, APDA president; Paul Maestrone, DVM, APDA director of scientific and medical affairs. Second row: Joel S. Perlmutter, MD; Richard Myers, PhD; Mary Maral Mouradian, MD; Marie-Francoise Chesselet, MD, PhD; Jacob I. Sage, MD. Third row: David G. Standeart, MD; James Bennett, Jr., MD, PhD; Erwin Montgomery, Jr., MD. Not present: Mahlon R. Delong, MD; Dennis Dickson, MD, and Ray L. Watt, MD.*



# APDA ADDITIONAL RESEARCH FUNDING FOR FISCAL YEAR 2004-2005

<b>Cotzias Fellowships</b>		
James Greene, MD, Ph.D.	Emory University, <i>Atlanta, GA</i>	Regulation of Energy Metabolism in Midbrain Dopamine Neurons
Clemens Scherzer, MD	Brigham and Women's Hospital <i>Boston, MA</i>	Lipid Modifiers of A-Synuclein Toxicity

<b>Roger C. Duvoisin, M.D., Fellowships</b>		
Erwin B. Montgomery, Jr., MD	University of Wisconsin, <i>Madison, WI</i>	

<b>Post-Doctoral Fellowships</b>		
Shankar J. Chinta, Ph.D.	Buck Institute for Age Research <i>Novato, CA</i>	Understanding the Role of Glutathione in the Etiology of Parkinson's Disease Using a Transgenic Animal Model
Tomas Falzone, Ph.D.	University of California, San Diego <i>La Jolla, CA</i>	Axonal Transport of Ubiquitin & Proteasome Degradative Machinery and its Role in Transport Regulation
Herman C. Lawson, MD	Johns Hopkins University <i>Baltimore, MD</i>	The Effect of Deep Brain Stimulation of the Sub-Thalamic Nucleus on the Speed of Internally Generated Movements and Motor Adaptation
Niklas Lindgren, Ph.D.	University of Pittsburgh, <i>Pittsburgh, PA</i>	Signaling Pathways Mediating the Neuroprotective Role of Exercise in Parkinson's Disease
Vanee Pho, Ph.D.	No. California Institute for Research and Education, <i>San Francisco, CA</i>	Transcriptional Control of Midbrain Dopaminergic Neurons by HIPK2 and Its Implications in the Pathogenesis of Parkinson's Disease
U. Shivraj Sohur, MD, Ph.D.	Massachusetts General Hospital <i>Boston, MA</i>	Induced Adult Neurogenesis in Corticostriatal Pathways
Michael J. Volles, Ph.D.	Brigham and Women's Hospital <i>Boston, MA</i>	A Functional Screen for Sequence Variants of Alpha-Synuclein with Enhanced Cytotoxicity to Dopaminergic Neuronal Cells in Culture
Donghua H. Zhou, Ph.D.	University of Illinois, <i>Urbana, IL</i>	Structural Studies of Vesicle Associated A-Synuclein by 3D Solid State NMR

<b>Research Grants</b>		
Charles L. Cox, Ph.D.	University of Illinois, <i>Champaign, IL</i>	Functional Contribution of the Parafascicular Thalamic Nucleus in Basal Ganglia Circuit Activity
Mark T. D'Esposito, MD	University of California, Berkeley <i>Berkeley, CA</i>	Defining the Cognitive Enhancing and Impairing Effects of Dopaminergic Medication in Parkinson's Disease
Benoit I. Giasson, Ph.D.	University of Pennsylvania <i>Philadelphia, PA</i>	Biochemical Comparison of Mutants of Alpha-Synuclein Causal of Parkinson's Disease
Maolin Guo, Ph.D.	University of Massachusetts <i>Dartmouth, MA</i>	Biochemical Characterization of a 1-CYS Peroxiredoxin — Relevant to the Antioxidant Defense of Parkinson's Disease
George R. Jackson, MD, Ph.D.	University of California, <i>Los Angeles, CA</i>	Effects of Mutant Human Parkin on Dopaminergic Neurodegeneration and the Misfolded Protein Response in Drosophila
Daniel Kaufman, Ph.D./ William Melega, Ph.D.	University of California, <i>Los Angeles, CA</i>	Can a Vaccine Inhibit Dopaminergic Neuron Degeneration in a Parkinson's Disease Animal Model?
Daniel A. Linseman, Ph.D.	University of Colorado School of Medicine, <i>Denver, CO</i>	Neurotoxin-Induced Changes in BH3-Only Protein Expression Analyzed by Real-Time PCR in Primary Dopaminergic Neuronal Cultures
Cameron McIntyre, Ph.D.	Cleveland Clinic Foundation <i>Cleveland, OH</i>	Electric Field Generated by Deep Brain Stimulation
Arnulfo Quesada, Ph.D.	University of California, <i>Los Angeles, CA</i>	Neuroprotective Mechanisms of Estrogen and Insulin-Like Growth Factor 1
Chad M. Rienstra, Ph.D.	University of Illinois, <i>Urbana, IL</i>	Structural Studies of A-Synuclein Fibrils By 3D Solid State NMR
Jean Christophe Rochet, Ph.D.	Purdue University, <i>West Lafayette, IN</i>	Antioxidant Activity of DJ-1 and its Parkinson's Linked Mutants
Joseph Mark Savitt, MD, Ph.D.	Johns Hopkins School of Medicine <i>Baltimore, MD</i>	The Use of Genetically Engineered Mice to Examine the Role of GDNF Signaling in the Development and Survival of Dopaminergic Neurons
Felix Schweizer, Ph.D.	University of California, <i>Los Angeles, CA</i>	A Role for Parkin in Synaptic Transmission
Edward A. Stern, Ph.D.	Massachusetts General Hospital <i>Boston, MA</i>	Effect of A-Synuclein Accumulation on Firing Patterns and Synaptic Targets of Nigrostriatal Dopamine Neurons
Kari Swartztrauber, MD, MPH	Portland VA Medical Center <i>Portland, OR</i>	Quality of Health Care for Patients with Parkinson's Disease: Evaluating Performance Outcomes
Patricia A. Trimmer, Ph.D.	University of Virginia, <i>Charlottesville, VA</i>	Mechanisms of Lewy Body Formation in a Culture Model of Sporadic Parkinson's Disease
Zuo-Zhong Wang, Ph.D.	University of Pittsburgh School of Medicine, <i>Pittsburgh, PA</i>	A Clonal Dopaminergic Cell Line for Transplantation Therapy of Parkinson's Disease
Gabriele Wulf, Ph.D./ Merrill Landers, Ph.D.	University of Nevada, <i>Las Vegas, NV</i>	Attentional Focus Training to Enhance Balance in Parkinson's Disease
Jin Xu, Ph.D.	Caritas St. Elizabeth's Medical Center <i>Boston, MA</i>	Transcriptional Regulation by DJ-1 in Neuronal Cells
Jianhua Zhou, Ph.D.	University of Massachusetts <i>Worcester, MA</i>	Interaction Between Parkin and RING Finger E3 Ligase RFP in Drosophila Models

<b>Summer Medical Students Fellowships</b>		
Eleanora Marnes	Finch University of Health Sciences <i>Chicago, IL</i>	

## CAREGIVER STRESS

The following are the most frequently observed signs of stress:

**1. Denial** — about the disease and its effects on the person who's been diagnosed.

**Ex:** I know Mom's going to get better.

**2. Anger** — at the person with Parkinson's or others; no effective treatments or cures currently exist, and people don't understand what's going on.

**Ex:** If he asks me that question one more time, I'll scream!

**3. Social withdrawal** — from friends and activities that once brought pleasure.

**Ex:** I don't care about getting together with the neighbors anymore.

**4. Anxiety** — about facing another day and what the future holds.

**Ex:** What happens when he needs more care than I can provide?

**5. Depression** — begins to break your spirit and effects your ability to cope.

**Ex:** I don't care anymore.

**6. Exhaustion** — makes it nearly impossible to complete daily tasks.

**Ex:** I'm too tired for this.

**7. Sleeplessness** — caused by a never-ending list of concerns.

**Ex:** What if she falls and hurts herself?

**8. Irritability** — leads to moodiness and triggers negative responses and reactions.

**Ex:** Leave me alone!

**9. Lack of concentration** — makes it difficult to perform familiar tasks.

**Ex:** I was so busy, I forgot we had an appointment

**10. Health problems** — begin to take their toll, both mentally & physically.

**Ex:** I can't remember the last time I felt good. ■

## MANAGING PARKINSON'S DISEASE

When Jules, age 72, was diagnosed with Parkinson's disease (PD) he worried that he would no longer be able to partake in one of his favorite activities — golfing. With medication, however, he was relieved to find that he was still able to play 18 holes of golf without too much trouble. Unfortunately, after a few years, Jules noticed that his medication wasn't controlling his symptoms as long as it once did.

"At first I was able to enjoy a full game of golf without my PD symptoms interfering," says Jules. "After a while though, I noticed that my symptoms were returning sooner than they did previously. It wasn't long before I could only play nine holes before I would lose feeling in my right side and have to quit. It was very frustrating."

Doctors call Jules' problem "wearing-off." It happens because the effects of a widely-used PD medication called levodopa literally "wear-off" over time and symptoms reappear before the next dose of medication.

Jules is not alone. According to Stuart Isaacson, M.D., director of the Parkinson's Disease & Movement Disorders Center of Boca Raton, Florida, "wearing-off" is unfortunately common among people with PD.

"Symptoms of Parkinson's disease do respond well to medical treatments. One of these treatments, levodopa, has been considered the cornerstone of Parkinson's disease therapy for nearly 40 years," says Dr. Isaacson. "Although levodopa is normally very effective when it is first used, nearly half of patients experience 'wearing-off' within one to two years of levodopa treatment."

"Wearing-off" can include both motor and non-motor symptoms. Movement-related symptoms may include trembling or shaking, muscle cramping, trouble speaking, general slowness or stiffness, and problems with balance. Non-motor symptoms may include anxiety, feeling restless, difficul-

ty breathing, insomnia or sleep disturbances, trouble thinking clearly, and lack of energy.

The good news is that motor symptoms of "wearing-off" can be successfully treated with newer medications that can help increase the time levodopa controls the symptoms of PD. But in order to treat "wearing-off," it must first be identified.

"If you think that you are experiencing 'wearing-off,' it is important that you discuss your symptoms with your doctor," says Dr. Isaacson. "The key is to keep track of your symptom control so your doctor can identify 'wearing-off' and explore treatment options."

A new, free-of-charge information and resource package (StEP kit) is available for people with PD that can help to identify the signs and symptoms of "wearing-off". The kit contains a diary to track when symptoms come back between doses of medication. The kit was developed by Novartis Pharmaceuticals Corporation in consultation with the American Parkinson Disease Association and other nationally recognized experts who specialize in PD.

In addition to information about "wearing-off," the kit includes treatment information, tips for caregivers, nutrition recommendations and suggestions for coping with the challenges of PD. Because staying active is so critical, the kit features a 30 minute exercise video designed specifically for people with PD.

"It's important to be educated about the challenges that you may face as a person living with PD says Jules. "Once I talked to my doctor about the problems I was experiencing with 'wearing-off,' he adjusted my medication. Now I'm back on the golf course, playing all 18 holes, and focusing on the game, rather than on my symptoms."

To order your free StEP Kit, call toll-free 1-866-STEP-KIT (1-866-783-7548), or visit <http://www.stepkit.net>. ■



# ADULT MEDICAL DAY CARE

## *a great alternative to nursing homes*

It is often a challenge for families to find the best environment for an elderly or disabled adult diagnosed with Parkinson's disease (PD), Alzheimer's disease or other disability. In the past, the only options were nursing homes or living at home with the assistance of a home health aide or a family member. Today, the continuum of care also includes a great alternative, Adult Medical Day Care.

An adult medical day care center is a structured environment for older and/or disabled adults. The center is staffed with licensed or certified professionals such as registered nurses, certified or licensed social workers, registered dietitians and certified recreation therapists. In some centers a certified nursing assistant or home health aide is also available to provide hygienic care to the client.

Nursing care provides an extra measure of support and is an integral part of adult medical day care. When a client is admitted to the program, a comprehensive assessment and care plan is prepared to address the client's medical and psychosocial needs. In addition, medication administration, blood sugar and other diagnostic testing is done to monitor the client's medical status.

When a change in medical condition is observed, a nurse is available to speak with the physician and the family to discuss possible interventions.

Recreational services provide a wonderful social outlet for older adults. In addition to socializing with peers, activities and trips are planned which are geared to each individual's physical and mental abilities.

Nutritional services are geared to

each individual's therapeutic requirements and cultural tastes.

Adult medical day care centers provide their clients' nutritional counseling, by a registered dietitian, in order to preserve or restore the client's health. Breakfast, lunch, dinner and snacks are served, and the meals are prepared based on the individuals' therapeutic diet and cultural tastes.

Family support groups provide family members with information and support. Some adult medical day care centers also offer family/caregiver support groups. Families and caregivers have an opportunity to share information, resources and experiences to help each other deal with their individual challenges.

Transportation provides an important link to medical and community services. This service typically operates during daytime hours and provides transportation to and from the client's home as well as to doctor appointments and community services (bank, grocery shopping, etc.)

While adult medical day care is covered completely by Medicaid, there are other sources of funding. The New Jersey State respite program will provide up to \$30,000 for families who qualify. The Alzheimer's Association provides a one-time grant of \$500 for those who qualify. In addition, many long-term care insurance policies also cover adult medical day care services and most centers have some type of established fee schedule for families who would like to pay privately. Keep in mind that

adult medical day care is typically less expensive than a nursing home.

When looking for an adult medical day care center for a family member, it is important to find the right center that can properly care for him or her. The following is a list of questions you will want to keep in mind when visiting the centers:

1. Is the location convenient and accessible? Is transportation available? Is there an additional charge for transportation or is it included in the day care fee? Can they suggest options?
2. Are service hours suitable for your situation?
3. What is the daily cost? Are meals and snacks included?
4. Are there hidden charges such as lunch fees, craft, supply fees, fees for outings, transportation?
5. Must one commit to a minimum amount of service, i.e., at least two days/week?
6. What is the policy concerning late arrival or late pick-up?
7. Do the services include family supportive programming such as caregiver support groups, social worker consultation, or referral services?
8. Are there hidden benefits, such as the availability of regular professional testing for blood pressure, annual immunizations, hair styling, bathing, dental check-ups, etc.?
9. What about programming for the participants throughout the day — such as exercise, music, crafts, memory sharing, etc.? Is there structured programming which maintains participants' abilities without being over-



# 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)
7. **Good Nutrition in Parkinson's Disease**  
26-page booklet (English, Italian, Swedish)
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**  
A 20-page booklet for patients and their families (English)
11. **My Mommy had PD... But It's Okay!**  
20-page booklet of young children.

## EDUCATIONAL SUPPLEMENTS

Hospitalization, Helpful Hints, Living Will, Oral Health Care, The Family Unit, Helping Your Partner, Nursing Homes, Long Term Care Insurance, Recreation and Socialization in Parkinson's Disease, Comtan Questions & Answers, Use of Comtan in the Treatment of Parkinson's disease, PD and the Emergency Room

## CARELINK (A cooperative APDA-GSK project)

You can now contact the APDA Information and Referral Center closest to you by dialing the toll free number 1-888-400-APDA (2732)

## 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, Video Library, etc.

## WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

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

*The material contained herein concerning the research in the field of Parkinson's disease and answers to readers, questions are solely for the information of the reader. It should not be used for treatment purposes, but rather as a source for discussion with the patient's own physician.*

# ADULT MEDICAL DAY CARE

*Continued from Page 11*

stimulating. Are individuals with dementia separated from other participants or included in activities?

10. Can the facility accommodate special physical or medical requirements such as:
  - Dispensing medicine?
  - Giving reminders about taking pills?
  - Assist with toileting or handle incontinence?
  - Communicating effectively with hearing impaired participants?
11. How is safety insured? How are behavior problems handled? Are there specific behaviors or care needs which would require your loved one's withdrawal from the program? Since PD is a progressive disorder, you need to find out how the facility is going to handle potential ones, such as:
  - Incontinence
  - Difficulties in speaking
  - Wandering
  - Special dietary requirements
  - Behavioral problems

Schedule a visit to the day care center. Tour and examine each facility for cleanliness, odors, room size, lighting, decorations, general atmosphere of the environment. Observe how meals are served; sample the food, if possible.

Observe and interview the staff. Ask about their qualifications and training. Have they been trained in dementia issues? What is the staff-participant ratio? What does the staff's attitude seem to be? Carefully watch verbal and non-verbal communication between staff and participants. ■

*Abstracted from an article published in the 2004 Spring Issue of the Parkinson's Bulletin of the New Brunswick, N.J. APDA I&R Center.*