

The American Parkinson Disease Association

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by The American Parkinson
Disease Association, Inc.

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Research Funding at Record High

By Paul Maestrone, DVM

Director of Scientific and Medical Affairs

The American Parkinson Disease Association (APDA) reached a record high mark in Parkinson's disease (PD) research support by awarding more than \$3.3 million in research grants, fellowships and support to Centers for Advanced Research for fiscal year 2006-07. A patient-support budget for the same period will be under consideration at a future date.

Selecting recipients for APDA research funding is already a formidable task, but this year's number of 149 applications and high quality of the proposals made it even more challenging for the 15 members of the APDA Scientific Advisory Board (SAB).

The APDA Executive Committee unanimously voted to accept the SAB's recommendations. Included in the 2006-07 budget are two additional Centers for Advanced Research, two two-year Roger Duvoisin, MD grants, 12 post-doctoral fellowships, and 34 research grants. Funding for the 3, three-year George C. Cotzias, MD fellowships, awarded in prior years, will be continued (see pg. 8 and 9).

The University of Alabama at Birmingham and the University of Pittsburgh were selected to become Centers for Advanced Research, joining Emory University School of Medicine, Atlanta; UMDNJ-Robert Wood Johnson Medical School, New Brunswick; Boston University School of Medicine, Boston; University of Virginia Medical Center,

Charlottesville, UCLA School of Medicine, Los Angeles, and Washington University Medical Center, St. Louis.

As part of the research support package, the Executive Committee also unanimously voted to recognize G. Frederick Wooten, MD, chair of the SAB, with the 2006 Fred Springer Award for his leadership of APDA's research program.

President's note: During this year's SAB meeting to evaluate the research proposals, a roundtable discussion revealed the concern of research leaders in attracting young physicians and scientists to the vital area of research. With hundreds of thousands of dollars in education loans to be addressed, fewer and fewer of the potential leaders needed for scientific breakthroughs can afford to enter a field where their work is dependent upon an ever shrinking source of funding.

With this financial phenomenon posing a real and significant threat, not only to our mission, but also to the overall field of medical research, the APDA Executive Committee voted to increase the research funding by an additional \$500,000 in order to fund all the applications that had attained the score recommended for approval. Added to an original \$300,000 increased budget, APDA increased this year's scientific research funding by \$800,000 bringing its 2006-07 contribution to research to a record \$3.3 million. -Vincent N. Gattullo

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

In years past Vermont conjured up thoughts of maple syrup and cheddar cheese. Then I recently learned about APDA's Vermont Chapter's Rock-a-thon. One hundred rocking chairs are set out on the lawn of the capital building in Montpelier, and thousands of dollars are raised for Parkinson's research by participants rocking away. Now, that is my kind of fund-raiser! So on the first weekend in June, I set my car's compass north anticipating a sun-filled, fun-filled weekend. It proved fun-filled, but also rain-filled. Torrential downpours continued throughout the day, relentlessly soaking chairs and people, causing balloons to droop, and creating interruptions in electrical service to microphones.

My anticipated crisp spring New England day was not to be, but there was a greater joy.

I was in awe as I watched these wonderful people who would not be deterred:

- persons with Parkinson's who led a Kazoo Band Parade down State Street to the capital, water running down their faces but not interfering with their music;
- volunteers making coffee and handing out cookies under the tent to which all the chairs had to be moved;
- participants rocking away as much to keep warm as to raise funds.

Chapter members were out in full force, the Information & Referral Center's medical director joined the rockers after his hospital duties, and the coordinator served as MC, keeping spirits up, announcing prizes and even doing a mean twist to the music of a volunteer DJ.

As I reflected during the drive home, at first I felt so sorry for those who worked so hard for what they hoped would be a perfect event. Then I came to realize that they had an even more successful event because they overcame the obstacle that every outdoor event planner fears. It was a perfect example of how people with PD live every day - turning an imperfect situation into a successful life. Adjusting to a disease they cannot escape, they find the fortitude and strength to live as fully as possible, with determination and a sense of humor.



APDA President Vincent Gattullo and Vermont I&R Coordinator Jean Baker, RN, rocking in the Montpelier rain.

I thought of the favorite saying of a

former track coach: the glory of a success is in direct proportion to the adversity overcome in achieving it.

June 3, 2006 was a glorious day in Montpelier, where the APDA chapter demonstrated what every individual Parkinson's disease patient and his/her caregiver do every day: they made their own sunshine.

A handwritten signature in black ink, appearing to read "Vincent N. Gattullo".

Vincent N. Gattullo
President

Educational Supplement # 21



*Educational supplement no. 21 entitled,
Dr. Andrew Weil's Recommendations for Healthy Aging
"I have Parkinson's disease so these don't apply to me, right?"
WRONG!*

*Authored by Cynthia Holmes, Ph.D.,
was added to the educational material distributed by APDA.*

*You can contact the APDA national office or one of the APDA I&R
Centers for your copy.*

Zelapar Approved For Use In Parkinson's Disease

On June 15, 2006 the Food and Drug Administration approved Zelapar® (selegiline HCl) orally disintegrating tablets, a once-daily adjunct therapy for Parkinson's disease patients being treated with levodopa/carbidopa who show deterioration in the quality of their response to this therapy.

Zelapar, a monoamine oxidase-B (MAO-B) inhibitor, is the first Parkinson's disease treatment to use a novel delivery system called Zydis® Technology, which allows the tablets to dissolve within seconds in the mouth and deliver more active drug at a lower dose.

The use of Zelapar as adjunctive therapy to levodopa/carbidopa has been shown to reduce "off" time, on average, by 2.2 hours per day. The most common adverse reactions were nausea, pain, insomnia, rhinitis and dyskinesia.



CLINICAL TRIALS AND PD

By Joseph Friedman

Director, APDA I&R Center
Kent Hospital, Warwick, RI

I attended a conference recently at which a very distinguished Alzheimer's disease researcher was bemoaning the lack of interest on the part of Alzheimer disease (AD) patients to volunteer in clinical trials.

Some large trials testing new drugs to slow down the disease progression were going much slower than expected. He had suggested that the large AD patient advocacy groups partner with the drug companies and the government agencies sponsoring the clinical trials to advertise on television. The goal would be to get the public to understand why we need patients to volunteer for these studies. When I told my colleague that we in the PD research community were having the same problem, he told me that the AD plan was to also get the PD organizations to help in the effort to recruit patients with all the diseases being studied.

No research, no advances. No patients volunteering for research protocols, no new drugs. It's as simple as that.

You can make a difference in our fight against PD.

There are three ways in which you can fight PD:

- 1) You can lobby congress to provide more funds for research. Write a letter to your congressional representatives.
- 2) You can raise money yourself.
- 3) You can participate in clinical research projects by being a subject if you have PD, or a control (non-PD person who is used for a comparison group). Ask your doctor or do a web search to see if there's a project for you.

It has been my observation that patients are increasingly reluctant to participate in clinical research. "I don't want to be a guinea pig." "I

don't want to take another pill." "I'm afraid of side effects." "What if I get the placebo?" "It's too much effort." "I'm too busy." "I don't like doing that sort of thing." "I don't like seeing doctors."

Some patients are afraid they'll get the active drug and some are afraid they'll get the placebo.

In studies trying to figure out who volunteers for studies and why they choose to participate, the answer is usually that people volunteer for altruistic reasons. They want to help others. Many of the studies we do in PD will not produce results that will help the people participating, although some will. Sometimes the results will take too long to obtain to help the people involved. Sometimes they are performed to learn how the brain works, rather than to fix a problem.

Let me provide some background. There are several different types of research on PD. There is "basic" research, which involves studies on animal or human brains. Biochemical pathways are explored. Drug and toxin effects are evaluated. Cell structures are examined. Stem cells are studied in test tubes or in animal brains. And you can help by raising money or by offering your brain for study once you are finished using it.

Normal people can also offer their brains for PD research so that scientists can compare the PD brain changes to the brains of people the same age who do not have PD. You can contact your doctor and discuss how to arrange for a brain donation upon your death. While many people find the idea of a brain donation upsetting, the truth is, if you don't remove it it simply rots. The brain removal does not affect the appearance

of the body, including the face, in any way. An open casket funeral is still possible.

Clinical research involves people. We may measure things, such as tremor, memory, speech, etc and simply see what happens over time, trying to make correlations, such as: if you have tremor early on is your PD going to progress slower or faster; if you have a voice problem are you more likely to develop swallowing difficulties? If you have slow reaction times are you more likely to get into a car accident? What PD features correlate with fatigue; etc.?

Many clinical research projects involve medication trials. We may be looking at the effect of an experimental new drug on PD, perhaps to slow disease progression, possibly to treat tremor, dyskinesia, hallucinations, gait freezing, or a million other things that can go wrong in PD.

The only way we learn whether a treatment works is to try it and the only way to reliably test it is in a well designed trial, usually, although not always, involving a placebo control group. A placebo control group means that one group of the trial, gets a placebo or dummy medicine. Patients and doctors are so often fooled by their great desire to see a medication be successful that in most studies everyone gets better. It's like the introduction to the radio show, *Prairie Home Companion*, in which Garrison Keillor describes his town, Lake Wobegone, "...where all the children are above average." In placebo controlled trials we look for the difference between the placebo effect and the active drug's effect, since both treatments usually are helpful.

The problem in several studies has been recruiting subjects. People with advanced disease are more

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: What role does physical therapy play in the treatment of Parkinson's disease?

A: Parkinson's disease does not cause muscle paralysis. It is very important to maintain maximal strength in your legs as this improves balance and prevents falls. Parkinson's disease causes a gradual loss of balance and it is the falling and the consequence of falling (fractures, head injuries) which leads to most of the physical disability. The therapy is usually initiated as 2-3 times a week sessions and then maintained as a once a week session. You could also exercise to maintain muscle strength as advised by your physician.

Q: My husband is 52 years old and has had Parkinson's

disease for 6 years. He gets severe right leg cramps at night and sometimes during the day. His right foot turns in and the big toe comes up. He is on Requip 1 mg and Sinemet 25/100 three times a day. What can we do?

A: This is most likely due to a withdrawal of the medication during the night but "cramps" during the day can also be misinterpreted as dyskinesia (writhing, twisting movements). These problems would best be alleviated by increasing the Requip dose and adding a night dose of Requip, trying to lower the Sinemet during the day and add Comtan to it, and perhaps also taking Sinemet CR and a muscle relaxant like clonazepam at bedtime. An anticholinergic like Artane or Cogentin may also help. Cramps during the day can sometimes be helped by using an ankle/foot orthotic, which supplies support to the foot.

Q: I understand that there are two new medicines which will be available soon for Parkinson's disease. What are they?

A: The two medications are both monoamine oxidase inhibitors that inhibit the breakdown of dopamine like selegiline (Eldepryl) which dissolves in the mouth and has been available since 1989. The first is called Zelapar. It is an orally absorbable form of selegiline which has a faster onset. The other medicine is called Azilect (rasagiline). It is more potent than selegiline and does not break down into amphetamines as does selegiline. Remember that all of these MAO-inhibitors are irreversible inhibitors and they do not wear off for 2-3 months after discontinuation. They should be used with caution when taking anti-depressants and should be stopped for at least a few weeks before surgery. ■

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.



FYI EDITOR: K.G. Whitford

SUMMER 2006 VOLUME XIII NO. VI

FYI. 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.

AND THE BEAT GOES ON

During their lifetime, neither composer Joseph Meyer nor his wife Rosalyn was associated with APDA. But one item in their will remains music to the ears all who benefit from their generosity.

Joseph Meyer was born in California in 1894, and at age 13 years old was sent to Paris for a year to study violin. After graduating from high school, he worked in a San Francisco café, served in the army during WWI and then worked in a mercantile business.

But in 1921 the showbiz bug bit and he abandoned the retail trade for New York City and Tin Pan Alley.

His first success was in collaboration with lyricist Harry Ruby. "My Honey's Lovin' Arms" was recorded by Benny Goodman and Isham Jones. A year later, his work with lyricist Buddy De Sylva produced "California, Here I Come." Thus began a 66-year-long career working with renowned lyricists such as Billy Rose, Irving Caesar and Ira Gershwin, and producing the scores for several Broadway shows including the Ziegfeld Follies and New Faces, and songs that include "Crazy Rhythm" and "If You Knew Susie Like I Know Susie."

The royalties of Mr. Meyer's music were bequeathed to APDA, and periodically checks ranging from \$58 to \$5,000 are received from the Songwriters Guild of America. To date, the legacy has brought more than \$75,000 to help APDA meet its mission to "Ease the Burden - Find the Cure" for Parkinson's disease.

The Meyers' decision to include APDA in their will is just one example of how estate planning and delayed giving can continue to help others after death.



Dr. Labunetz addressing the April 2005 Awareness in the Montana capitol.

Thanks, Dr. Labunetz

Dr. William Labunetz has been APDA's presence in Montana since the opening of its Great Falls I&R Center in the mid-1980s and has worked with four coordinators in expanding services for Parkinson's disease patients throughout the northwest ever since. The Montana center also provides services for North Dakota and Wyoming. This spring Dr. Labunetz retired after 39 years of neurological practice.

Lydia Skoog, who has been the coordinator for the past six years, says his sense of humor is one thing she will miss. "He was always telling jokes at our symposia or support group meetings. One of his favorites was, 'If you are in a burning

building, follow a Parkinson's patient out; they can't walk well sometimes, but they can run!'"

Dr. Labunetz is a relocated Easterner. He received his medical degree from Jefferson University Medical College, Philadelphia, and completed an internship at the former Misericordia Hospital, now Mercy Hospital, also in Philadelphia.

"I have learned a lot from him over the years. He is a good teacher. Although he had a general neurology practice, he had a heart for the Parkinson's patient and went the extra step many time," Lydia says adding, "I wish him well and hope he is enjoying his retirement. Thanks, Dr. Labunetz."

Everyone at APDA echoes her wishes.

In the Northeast

APDA's own art patron has had another Meet the Artist Gallery Show success at Robert Wood Johnson University Hospital. New Jersey coordinator Elizabeth Schaff began with a calendar featuring artwork by Parkinson's patients three years ago, which led to stationery, which led to last year's first exhibit in which mixed-media artists could participate. Five new artists joined this year's show, and Elizabeth has also introduced an art class series, "Painting with Parkinson's."

Proclamations for Parkinson's awareness are still coming in. Massachusetts chapter president Keith Ciccone, received documents from Gov. Mitt Romney, and William J. Phelan, Mayor of Quincy.

Congratulations to the "wet wonders of Vermont!" (See president's message.) Leading the way to another successful Rock-a-thon were acting president Michael O'Connor, chapter coordinator, Nicky Cribb, I&R director, Dr. Robert Hamill, and coordinator Jean Baker, and stalwart volunteers Bruce Talbot, Susan Werntgen, Shirley Jacobs, Judith Hebert and Cassie Blanchard.

In the South

Coordinating the annual three-day Young Onset Parkinson's Retreat for patients and their families is challenging enough; enter Mother Nature destroying the entire coast where it is held makes it even more so. But that is exactly what coordinators Carla Cothran (Birmingham Alabama), Caryn Crenshaw (Nashville, Tennessee) and Brenda Allred (Vicksburg, Mississippi) did, albeit with a

year's hiatus to recoup from Hurricane Katrina, and relocate the venue from Ocean Springs, Miss. to Townsend, Tenn. The retreat included daily aquatic exercise, lectures by physicians including Vicksburg's I&R director Dr. Lee Voulters, patient and caregiver encounter groups, lots of family fun time, and concluded with a hillbilly hoe-down. Ken Stuck, credited with being the impetus behind the retreat five years ago, was also this year's star. Ken was just able to move at the last retreat, but following deep brain stimulation, was singing and dancing with his new bride at this year's!

Brenda is also busy working with Memorial Hospital in Gulfport, Mississippi to raise PD awareness. An initial meeting took place at the hospital, which will host monthly support group meetings.

In the North

What do you call a coordinator who greatly expanded services throughout her state, made more than 50 presentations reaching more than 1,500 people, helped raise \$15,000 for research and more than \$17,000 in unrestricted grants, organized two public forums and assisted in creating six new support groups? You call her Paulette Olsen, APDA's Minnesota I&R coordinator and a winner of Abbott Northwestern Hospital's Employee Recognition Award. Paulette has also helped develop materials on PD for the hospital's block nurse program and launched a program for newly diagnosed patients called "The Good Start Project."

Jessica Hahn has two major symposia planned for the fall in Wisconsin: APDA's Scientific Advisory Board member Dr. Erwin Montgomery, Jr., will discuss the "Medical Management of PD," Sept. 23, at the Holiday Inn Hotel and Convention Center, Stevens Point; and another at the Health Sciences Learning Center, Madison, on Oct. 1.

In the Midwest

The Iowa Chapter has discovered that golf can be fun ... and rewarding. Tentatively calling its first greens fund-raiser the Inaugural Parkinson's Invitation Golf Tournament, the chapter raised more than \$11,000, attracting 31 teams and sponsors for all 18 holes at the Beaver Creek Golf Club in Grimes, Iowa. "Those who didn't play contributed prizes," reports a very happy president Barbara Moore, who notes that this will become an annual event.

The artwork of Nancy Paschke, who was diagnosed with PD at age 33 and has dealt with its effects for more than 30 years, will be featured at a Sept. 17 exhibit, "The Art of Living with Parkinson's Disease", in Northbrook, Illinois. APDA's young on-set coordinator Susan Reese is encouraging people with Parkinson's to join the event being presented in partnership with the Bernard Weinger Jewish Community Center.

There was an Elvis spotting in Nebraska! It was when the chapter's walk-a-thon June 4, during which more than 300 participants (some canine) turned out and raised more than \$13,000 for research. The Country Kickers, an Omaha dance group, provided the entertainment.... including the king.

In the Southwest

Little wonder that more than 400 people are expected at the "Power Over Parkinson's Conference," in Phoenix, Ariz. on Nov. 11. Former U.S. attorney general Janet Reno, and Dr. Michele Tagliati of Mount Sinai School of Medicine, NYC, a leader in deep brain stimulation surgery, are scheduled to speak. The full-day event at the Desert Ridge Marriott will include continental breakfast, vendor displays, luncheon and time to socialize, in addition to lectures.

Coordinators' Conference Held in Philadelphia

APDA's annual coordinator's conference was held in Philadelphia, July 27-30. More than 75 attendees and 45 coordinators from across the United States heard scientific presentations presented by two renowned neurology professors, Lawrence Golbe, MD, of UMDNJ Robert Wood Johnson Medical School, New Brunswick, N.J., and Joseph Friedman, MD, of Brown University, Providence, R.I.; participated in case study reviews and panel discussions addressing new programs and "hot topics", and renewed friendships and professional camaraderie.

Minneapolis, Minn. coordinator, Paulette Olsen; Jean Baker, Burlington, Vt. coordinator; and Lydia Skoog of Great Falls, Mont. received the 2006 Salvatore A. Esposito Award during the farewell dinner on Saturday night in the Westin Hotel.

Congratulations were sent to Memphis, Tenn. coordinator Gina Cici, who gave birth to Sophia Marie in April. Mary Louise Weeks, who brought four-month old Charlotte Louise all the way from Atlanta, Ga., was given warm APDA congratulations in person.

APDA Adds Two New I&R Centers Four New Coordinators and a New Medical Director

Phoenix, Ariz. and Shreveport, La. are homes of the newest APDA I&R Centers. Drs. Padma Mahant, and Johan Samata, are co-directing the Phoenix center, located at Banner Good Samaritan Medical Center. Thomas Vivano is the coordinator.

Rhonda Feldt, RN, has been named the coordinator in the newly opened Shreveport center with Dr. Richard Zweig serving as medical director.

Shari Powell, RN, MPH, has been named coordinator of the Baltimore, MD, center where Kathy Pear has been serving as acting coordinator, and Martha Gardner, RN, MSN, is the new coordinator at the Stanford, Calif. center.

Dr. Ernesto Garza had been appointed the medical director of APDA's Albuquerque, N.M. I&R Center.

40% donation to PD research



Flower power for Parkinson

Help APDA in the fight against Parkinson's disease while making a beautiful visible statement in your garden next spring.

A package of 25 breathtaking red tulips with a small white edge, the traditional symbol of hope for Parkinson's disease, will arrive at your home directly from a producer of Holland's highest quality tulips in time for National Planting Day, Oct. 15. The price per bag, \$29.95, includes all shipping and handling charges.

The best part is that APDA will receive 40% of the price, excluding shipping costs, for every package purchased. These bulbs make wonderful gifts and are appropriate for balcony and patio containers as well as gardens.

Clip the coupon below and mail it with a check payable to TulipWorld, Inc., or completed credit card information to: APDA, 135 Parkinson Ave., Staten Island, NY 10305.

Orders must be received by Sept. 15, 2006

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Or enclose check made payable to TulipWorld Inc.

How many packages do you want to order?

Packages	Price per package	Total amount
	\$ 29.95	

Signature _____

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** for delivery of invoice and FedEx tracking code

APDA RESEARCH FUNDING FOR FISCAL YEAR 2006-2007

Centers for Advanced Research		
Emory University School of Medicine <i>Atlanta, Ga</i>	Robert Wood Johnson Medical School <i>New Brunswick, NJ</i>	Boston University School of Medicine <i>Boston, MA</i>
University of Virginia Medical Center <i>Charlottesville, VA</i>	Washington University Medical Center <i>St. Louis, MO</i>	UCLA School of Medicine <i>Los Angeles, CA</i>
University of Pittsburgh <i>Pittsburgh, PA</i>	University of Alabama <i>Birmingham, AL</i>	
Cotzias Fellowships		
James Greene, MD, PhD	Emory University, <i>Atlanta, GA</i>	Regulation of Energy Metabolism in Midbrain Dopamine Neurons
Joseph M. Savitt, MD, PHD	John Hopkins Hospital, <i>Baltimore, MD</i>	Conditional GDNF Receptor Knockout Mice: Exploring the Role of GDNF in Dopaminergic Cell Development and Survival
Clemens Scherzer, MD	Brigham and Women's Hospital, <i>Boston, MA</i>	Lipid Alpha-Synuclein Toxicity
Roger Duvoisin, MD Fellowship		
James L. Roberts, MD, Ph.D.	University of Texas Health Science Ctr. <i>San Antonio, TX</i>	Molecular and Cellular Mechanisms of Estrogen Mediated Neuroprotection of Mesencephalic Dopaminergic Neurons
Evan Y. Snyder, MD, PhD.	The Burnham Institute, <i>La Jolla, CA</i>	Human Neural Stem Cells for Dopamine Reconstitution. Spontaneous Versus Directed Differentiation
PostDoctoral Fellowships		
Marie Olivia Casanueva, Ph.D.	Northwestern University, <i>Evanston, IL</i>	The Role of Neuronal Excitation in the Folding Properties of Alpha- Synuclein in Caenorhabditis Elegans
Susan Criswell, MD	Washington University School of Medicine, <i>St. Louis, MO</i>	Parkinsonism and Manganese Toxicity in Patients with End Stage Liver Disease
Suk Yun Kang, MD	National Institutes of Health, <i>Bethesda, MD</i>	Fatigue in De Novo and Advanced Parkinson's Disease
Morvarid Karimi, MD	Washington University School of Medicine, <i>St Louis, MO</i>	Mechanisms of Chronic DBS Stimulation in Non-Human Primates
Donna Lee, Ph.D.	The Buck Institute for Age Research, <i>Novato, CA</i>	Mechanisms of Iron Chelation as a Novel Therapy for Parkinson's Disease: Involvement of the HIF Pathway
Daniel Lightfoot, Ph.D.	The Scripps Research Institute, <i>La Jolla, CA</i>	Contribution of Chromosomal Anueploidy to Disease Pathology in Sporadic Parkinson's Disease
Cristina Malagelada, Ph.D.	Columbia University, <i>New York, NY</i>	RTP801 as a Negative Regulator of Akt in Parkinson's Disease
Charbel El Hajj Moussa, Ph.D.	Caritas St. Elizabeth's Medical Center, <i>Boston, MA</i>	Parkin Promotes Alpha-Synuclein and Beta-Amyloid Toxicity and Protects against Their Effects on Tau Pathology.
Subhojit Roy, MD, Ph.D.	University of Pennsylvania, <i>Philadelphia, PA</i>	Axonal Transport and Synaptic Targeting of Normal and Mutant Alpha-Synuclein
Jessica Smerz, Ph.D.	Cleveland Clinic Foundation, <i>Cleveland, OH</i>	Effect of Cerebral Atrophy and White Matter Changes on Neuropsychological Outcome of Bilateral STN DBS for PD
Danqing Xiao, Ph.D.	Massachusetts General Hospital, <i>Boston, MA</i>	The Role of EphA4 in L-Dopa Induced Dyskinesia in a Mouse Model of Parkinson's Disease
Talene Yacoubian, Ph.D.	University of Alabama, <i>Birmingham, AL</i>	Role of 14-3-3 Proteins in Alpha- Synuclein-induced Neurotoxicity
Research Grants		
Rajeshwar Awatramani, Ph.D.	NORTHWESTERN UNIVERSITY <i>Evanston, IL</i>	Uncovering Molecular Cascades Involved in Midbrain Dopaminergic Neuron Specification.
Sarah Berman, MD, Ph.D.	UNIVERSITY OF PITTSBURGH <i>Pittsburgh, PA</i>	Mitochondrial Dynamics in Vulnerability and Protection of Aging in Parkinson's Disease
Mark Bevan, Ph.D.	NORTHWESTERN UNIVERSITY <i>Chicago, IL</i>	Cellular Mechanisms Underlying the Therapeutic Benefit of High Frequency Stimulation of the Subthalamic Nucleus for Parkinson's Disease
Christopher Bishop, Ph.D.	BINGHAMPTON UNIVERSITY, <i>Binghamton, NY</i>	Dorsal Raphe Regulation of L- Dopa- Induced Dyskinesia
Yvette Bordelon, MD, Ph.D.	REED NEUROLOGICAL RESEARCH <i>Los Angeles, CA</i>	Intraneuronal Aggregate Labelling with Positron Emission Tomography in Parkinson's Disease
Shankar Chinta, Ph.D.	BUCK INSTITUTE FOR AGE RESEARCH, <i>Novato, CA</i>	Proteomic Analysis of Dopaminergic Mitochondrial Complex I Following Chronic Rotenone Exposure: Implications for Parkinson's Disease

APDA RESEARCH FUNDING FOR FISCAL YEAR 2006-2007

(continued from page 8)

Research Grants		
Gammon Earhart, Ph.D.	WASHINGTON UNIVERSITY SCHOOL OF MEDICINE, <i>St. Louis, MO</i>	Can Dance Improve Functional Mobility in Parkinson's Disease?
Thomas Eckert, MD	THE FEINSTEIN INSTITUTE, <i>Manhasset, NY</i>	Imaging Assessment of Levodopa Washout in Parkinson's Disease
Emad Eskandar, MD	MASSACHUSETTS GENERAL HOSPITAL <i>Boston, MA</i>	Abnormal Subthalamic Activity in Parkinson's Disease
Sheila Fleming, Ph.D.	UNIVERSITY OF CALIFORNIA, <i>Los Angeles, CA</i>	Effects of Oxidative Stress in Genetic Mouse Models of Parkinsonism
Robert Gross, MD, Ph.D.	EMORY UNIVERSITY, <i>Atlanta, GA</i>	Inhibiting Inhibitors of Nigrostriatal Pathway Regeneration with a Novel Lentiviral C3 Vector
Kari Hoyt, Ph.D.	OHIO STATE UNIVERSITY, <i>Columbus, OH</i>	Chronic Biguanide Exposure as a New Mouse Model of Parkinson's Disease
Eric Huang, MD, Ph.D.	UNIVERSITY OF CALIFORNIA, <i>Sans Francisco, CA</i>	Role of TGF β -HIPK2 Signaling in Protecting MPTP- Induced Toxicity to Dopamine Neurons
Syed Imam, Ph.D.	UNIVERSITY OF TEXAS HEALTH SCIENCE, <i>San Antonio, TX</i>	Evaluation of Stress-Induced Tyrosine Kinase, C-Abl, as a Novel Therapeutic Target for Parkinson's Disease
Toshihiro Kitamoto, Ph.D.	UNIVERSITY OF IOWA, <i>Iowa City, IA</i>	Identification of Novel Genes that Enhance or Suppress Dopaminergic Neurodegeneration Using the Drosophila Forward Genetic Approach.
Andreas Kottman, Ph.D.	COLUMBIA UNIVERSITY, <i>New York, NY</i>	On the Function of Sonic Hedgehog Expressed by Mesencephalic Dopaminergic Neurons in the Adult Brain
Weidong Le, MD, Ph.D.	BAYLOR COLLEGE OF MEDICINE, <i>Houston, TX</i>	Essential Role of Iron in Proteasome Inhibitor-Induced Nigral Cell Degeneration and Protein Aggregation.
Rehana Leak, Ph.D.	UNIVERSITY OF PITTSBURGH, <i>Pittsburgh, PA</i>	Preconditioning-induced Neuroprotection in Models of Parkinson's Disease
Marie Legare, DVM, Ph.D.	COLORADO STATE UNIVERSITY, <i>Fort Collins, CO</i>	Effects of DJ-1 Mutation on Astroglial Cellular Function
Changwei Liu, Ph.D.	UNIVERSITY OF COLORADO HEALTHSCIENCE, <i>Aurora, CO</i>	Biochemical Studying of a Vicious Cycle of Toxicity between the loss of Proteasome Activity and the Alpha-Synuclein Aggregation.
Pamela McLean, Ph.D.	MASSACHUSETTS GENERAL HOSPITAL, <i>Boston, MA</i>	Studies of Alpha-Synuclein Dimerization using Bimolecular Fluorescence Complementation
Gary Miller, Ph.D.	EMORY UNIVERSITY, <i>Atlanta, GA</i>	A Novel Model of Parkinson's Disease Based upon Altered Vesicular Storage of Dopamine
Brit Mollenhauer, MD	BRIGHAM AND WOMEN'S HOSPITAL, <i>Boston, MA</i>	Evaluation of Cerebrospinal Fluid Alpha-Synuclein as a Biomarker for Synucleinopathies
Darren Moore, Ph.D.	JOHNS HOPKINS UNIVERSITY, <i>Baltimore, MD</i>	Generation and Characterization of LRRK2 Conditional Transgenic Mice as a Novel Model of Parkinson's Disease.
Chad Rienstra, Ph.D.	UNIVERSITY OF ILLINIOS, <i>Champaign, IL</i>	Structural Studies of Membrane Bound Alpha-Synuclein by 3D Solid State NMR
Jean Cristophe Rochet, Ph.D.	PURDUE UNIVERSITY, <i>West Lafayette, IN</i>	Alpha-Synuclein Toxicity in Parkinson's Disease: Role of ER Stress
Neeta Roy, Ph.D.	WEILL MEDICAL COLLEGE OF CORNELL UNIVERSITY, <i>New York, NY</i>	Transplantation of Neurogenin-2 Defined Dopaminergic Progenitors Isolated from Human Embryonic Stem Cells in Animal Model of PD
Wanli Smith, MD, Ph.D.	JOHNS HOPKINS UNIVERSITY, <i>Baltimore, MD</i>	MAPK Signaling and Mutant LRRK-2 Induced Cell Death
Ronald Tjalkens, Ph.D.	COLORADO STATE UNIVERSITY, <i>Fort Collins, CO</i>	Targeting Glia in Parkinson's Disease: Modulation of Astrocyte Inflammatory Phenotype by Orphan Nuclear Receptors
Kala Venkiteswaran, Ph.D.	PENN STATE HERSHEY MEDICAL CENTER, <i>Hershey, PA</i>	Dopaminergic Properties of Modified Human Retinal Pigment Epithelial Cells
Mark Wilson, Ph.D.	UNIVERSITY OF NEBRASKA, <i>Lincoln, NE</i>	The Mechanism of Redox Regulation of the Parkinsonism Associated Protein DJ-1
Jianhua Zhang, Ph.D.	UNIVERSITY OF ALABAMA, <i>Birmingham, AL</i>	Lysosomal Dysfunction-Induced Cell Death and Parkinson's Disease
Wei Zhang, MD, Ph.D.	UNIVERSITY OF TEXAS, <i>San Antonio, TX</i>	The role of Attractin and Mahogunin in Parkinson's Disease
Zhuohua Zhang, Ph.D.	BURNHAM INSTITUTE, <i>La Jolla, CA</i>	Pathogenic PINK 1 Mutants in Drosophila

EXELON[®] APPROVED TO TREAT PARKINSON'S DISEASE

The risk of developing dementia is approximately four to six times higher among Parkinson's patients than among elderly people without the disease.

The Food and Drug Administration (FDA) has recently approved Exelon[®] (rivastigmine tartrate) for the treatment of mild to moderate Parkinson's Disease (PD) dementia, making Exelon the first medication available for the treatment of this condition. Exelon is also approved for treatment of mild to moderate Alzheimer's disease.

The approval of Exelon for the treatment of PD dementia follows a unanimous recommendation in favor of approval from the FDA's Peripheral and Central Nervous System Drugs Advisory Committee on May 17, 2006, based on results from the Exelon in Parkinson's disease dementia study EXPRESS. EXPRESS is the first large-scale, randomized, double blind, placebo-controlled, multicenter study with an Alzheimer's disease medication to demonstrate statistically significant improvement in the treatment of symptoms of PD dementia.

STALEVO'S EVALUATION IN EARLY PARKINSON'S DISEASE

Novartis is now enrolling patients in FIRST STEP, an important Parkinson's disease (PD) study to investigate if Stalevo[®], (which, contain carbidopa, levodopa and entacapone), provides greater symptomatic benefit in comparison to the standard formulation of carbidopa at the same levodopa dosage level, when used as the initial therapy in early Parkinson's disease.

Stalevo tablets are currently indicated for PD patients with signs and symptoms of end-of-dose wearing off. Wearing off occurs when the effect of one dose of levodopa medication does not last as long as it used to.

"So far, the clinical use of Stalevo has focused on Parkinson's disease patients with end-of-dose wearing off," said Robert A. Hauser, M.D., M.B.A., director of the Parkinson's Disease and Movement Disorders Center of the University of South Florida in Tampa.

"However, if Stalevo, as initial levodopa therapy, provides better symptomatic benefit than the standard formulation of carbidopa/levodopa, these findings could have important clinical implications for the treatment of early Parkinson's disease patients."

The 39-week multi-national, multi-center, randomized, double-blind

controlled study will enroll approximately 424 patients in 53 study centers in North America and Europe. Patient recruitment began in August 2005 and is estimated to continue for 12 months. The first study results are expected in 2007.

Patients with Parkinson's disease, between 30 and 80 years of age, who have been diagnosed with idiopathic Parkinson's disease within the last five years and require initiation of levodopa therapy, will be randomized into the study. Investigators will assess patients' ability to perform activities of daily living and patients' motor function abilities using the Unified Parkinson's Disease Rating Scale (UPDRS Parts II&III). FIRST STEP is part of a major research initiative to better understand the potential of Stalevo in the treatment of Parkinson's disease.

Another study, STRIDE-PD, is ongoing in collaboration with Orion Pharma, Finland, and involves 740 patients at 70 centers. It is the first long-term, prospective, double-blind, controlled, multi-center Parkinson's disease study investigating whether Stalevo can delay the onset of dyskinesias in patients, compared to those taking only levodopa with carbidopa.



APDA Seed Money for Research

Anyone who ever tried to raise funds knows that it is not an easy task on any level.

In the world of scientific research, however, the ability to obtain the dollars needed to test, retest and proceed to the next level of testing, takes just as much talent and tenacity as conceiving the original hypothesis and plan of study.

The federal government is the leading and most prestigious funder of scientific and medical research in the United States. Monies are awarded by the National Institutes of Health (NIH), in Bethesda, Maryland, which provides billions of dollars every year for research. During fiscal year 2003 NIH provided close to \$11 billion to medical schools in the United States, and its National Institute for Neurological Disorders and Stroke, which is the major funder for Parkinson's disease research, had a billion dollar budget for the same year.

While the amount of money the government spends on health and research seems staggering, the cost for research is equally staggering and the process to qualify for those dollars is complicated and very competitive. That is why when the APDA funded research project of Dr. Bari Hoffman-Ruddy's 2002-2003 study, "Respiratory Muscle Training in Individuals with Parkinson's Disease" was awarded an NIH grant last year, it was considered a major achievement toward the next step of this highly innovative research.

The original APDA-funded study involved more than 30 people with PD. It employed the use of an expiratory pressure threshold device to test the outcome of its use for training and strengthening respiratory muscles to increase expiratory force. The initial findings showed that the program positively impacted respiratory and laryngeal dysfunction associated with PD. The grant work under the APDA

funding was just a pilot trial and there was no control of other factors like the severity of the PD.

Christine Sapienza, Ph.D., Dr. Hoffman-Ruddy's associate and the principle investigator on the NIH application, wrote that "The funding provided by the APDA enabled us to collect substantive preliminary data and led to the successful application and funding for continued work in patients with PD." The investigators have acquired other grants to study the effects of the training program on multiple respiratory physiologic functions. These grants are now approximately \$1 million.

It is very rewarding when the funds awarded by APDA not only enabled the support for the initial basic research, but also represented the seed money responsible for a much greater funding of a procedure that will help people with Parkinson's disease.

AIR TRAVEL SUGGESTIONS

There have been recent reports of Parkinson's disease (PD) symptoms being misinterpreted by security people, resulting in an extreme case in Canada in the incarceration of a patient visiting from another country and his expulsion.

- Anxiety and stress can increase PD symptoms so make sure to give yourself lots of extra time.
- Remember to dress casually and wear garments that are easy to remove because you often have to remove jackets, shoes, and belts to go through security.
- Travel as lightly as possible. If you want coffee and a snack, it is best to pick it up after you've made it through security so you don't have it tying up your hands.
- Make arrangements with your airline directly if you are going to need assistance, or if you will need special clearance to allow medical equipment or services to go beyond the security checkpoint, to assist you with boarding or deplaning.
- When making reservations for a hotel and ground transportation, ask for special accommodations you may require and confirm the arrangements 24 hours prior to departure.
- Before traveling to the airport, check your airport's Website for current parking, ground transportation, and traffic information.
- Most airlines have SkyCaps who can assist you with curbside check-in and arrange for passenger assistance between the curb, ticket counter, boarding area and plane.
- When checking in at the ticket counter, let them know you have PD and that it can slow you down. If your gate is distant and you are not up to the walk, request assistance from the ticket agent.
- Always put medications in your carry-on luggage. You never know if your checked baggage will meet you at your final destination, and when!
- Carry a list of your medications with their chemical and trade names and dosages, it may facilitate refills in a foreign country if so needed.
- Carry a card that says you have Parkinson's. It is available thru APDA national office or I&R Centers and says who your emergency contact person is, and any allergies you might have.
- If you are going to be changing time zones during your travels, speak with your doctor beforehand to plan your medication adjustments.

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 faxing to 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, Healthy Aging, 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 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/ A weekly-updated source of world news.

Clinical Trials and PD *cont. from page 3*

interested in research than milder patients, probably because the milder ones don't want to face the future and hope against hope that they don't "need" anything new.

Too many patients don't fully appreciate the fact that every pill they take for PD was the result of PD patients decades ago volunteering to be in experimental trials. They have no idea of the number of people who have been in trials that didn't work or trials in which the drug had a side effect. Some trials are stopped because the drug company decided that the new medication was not any better than the ones already available, or trials in which one company merged with another that had a competing drug more advanced in testing. Usually trials are stopped for good reason. Sometimes not. We researchers can't always control this.

Good research relies on good investigators and volunteer subjects. There are many attributes that we researchers share. Perhaps the most important is concern for our patients' safety. Safety is always our number one concern.

While we can never provide complete assurance that nothing bad will happen when a person enrolls in a trial, we certainly do our best to make sure that nothing bad happens. I can guarantee though, with 100 percent certainty, that nothing good will happen if people don't sign up for the research studies.

Some useful Websites for information about clinical trials in Parkinson's disease are:

www.pdtrials.org This site includes up-to-date information on PD clinical trials currently enrolling participants in the United States.

www.ninds.nih.gov This site includes information on research conducted by the National Institute of Neurological Disorders and Stroke.

www.parkinson-study-group.org The Parkinson Study Group (PSG) is a non-profit, cooperative group of Parkinson disease experts from medical centers in the US and Canada participating in clinical research.

www.apdaparkinson.org Visit our website for information to locate your nearest APDA Information and Referral Center. Coordinators will assist you in identifying clinical trials ongoing in your area.