

The American Parkinson Disease Association

W I N T E R 2 0 0 5 N E W S L E T T E R

The American Parkinson Disease Association

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by The American Parkinson
Disease Association, Inc.

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Stem Cell Research in Parkinson's Disease

By Curt R. Freed, M.D.

*Professor and Head, Division of Clinical Pharmacology and Toxicology
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Parkinson's disease is caused by the death of a small number of nerve cells that produce the chemical dopamine. Without dopamine, movement is impossible. All creatures from fruit flies to people use dopamine in their brains to control movement. Normally, a person has about a half million dopamine-producing cells located in an area at the bottom of the brain called the substantia nigra, or "black substance." That name was given because dopamine neurons are filled with black pigment. L-DOPA taken in a formulation like Sinemet gets converted to dopamine in the brain and improves movement in most patients for many years.

At the University of Colorado, we have pioneered a new treatment for Parkinson's disease (PD), replacing dead dopamine cells with fetal dopamine cells. Sixteen years ago, in November 1998, my neurosurgical colleague Robert Breeze, MD, and I performed the first fetal dopamine cell transplant into an American patient with Parkinson's. Since that time, we have operated on 61 people, most of whom had PD for at least 10 years. To qualify for the transplant, nearly everyone had failed conventional drug treatment because of problems like drug-induced dyskinesias. In the mid-1990s, we teamed up with neurologists Stanley

Fahn, MD, of Columbia University in New York City and David Eidelberg, MD, of North Shore University Hospital on Long Island, to do the first stringent test of brain-cell transplantation, in which, half the patients got cells transplanted into the brain and the other half had holes drilled in the skull but no cells implanted. The patients and their neurologists agreed that they would not find out which operation was done until one year after the surgery so that we could compare real cell transplants with the "placebo" surgery. The National Institutes of Health funded the study.

We found that transplants grew in nearly everyone regardless of his/her age and in spite of the fact that no one got immunosuppressant drugs. Transplants improved the ability to move before people took their first doses of drug in the morning, during the so called "off" phase. The original interpretation of the study was that patients over age 60 did not get better. That has turned out not to be correct. We found that the likelihood of responding to the transplant was completely dependent on how much people improved while taking the drug L-DOPA. If a person could look nearly normal while taking L-DOPA, transplants could make them function nearly normally. For the average person in

continued on page 3 1

STALEVO INITIAL THERAPY

Novartis and Orion Pharma announced a new study called STRIDE-PD (STalevo® Reduction In Dyskinesia Evaluation) to investigate if, when used as an initial therapy, Stalevo (a medication containing carbidopa, levodopa and entacapone in one tablet) delays the onset of dyskinesia for a longer time than the traditional formulation of levodopa/carbidopa.

The STRIDE-PD study will enroll approximately 740 patients in 14 countries worldwide. Patients between the ages of 30 and 70 years who have been diagnosed with idiopathic PD in the last five years and require the treatment of levodopa will be eligible for the study. Enrollment began in September and will continue for 12 months. The first study results are expected in 2007. For information, visit www.novartisclinicaltrials.com and click on [Parkinson's Disease Study A2401](#). ■

NO PUBLIC SUPPORT

APDA receives no government or other public funds and is entirely dependent upon contributions from businesses, foundations, but mostly from individuals. Gifts can be made by mail, telephone, fax or e-mail:

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PRESIDENT'S MESSAGE



Dear Reader,

An acquaintance, a retired paralegal in a large Manhattan law firm, was recently diagnosed with PD. She knew something “was not right” physically because she had problems moving in bed at night and getting up in the morning. Being a widely read person, she was well aware of the many possible diagnoses. “When the doctor told me it was Parkinson’s disease, I said, ‘Thank God.’ I was so relieved that it wasn’t Multiple Sclerosis or ALS or any of the other possibilities.”

I often hear Parkinsonians, like the reigning Ms. Senior New York State Carol Lenz, who says, “PD is a gift that has slowed me down and makes me cherish every moment.”

Of course, everyone would like to be rid of anything interfering with his/her perfect health. Kidney and diabetic patients maintain love-hate relationships with their lifesaving dialysis machines and insulin hypodermics. For the acne-afflicted teenager, those pimples are as traumatic as any major illness. I, myself, often shake my head when I have to reach for a cane to help me simply walk across a room after being a world-class hammer-throwing competitor.

What makes a diagnosis of Parkinson’s disease so different? Is it that it is not a death sentence like some rapidly growing cancers and heart diseases, or a state of prolonged paralysis, as some strokes can be? Is it the examples we have of people from Pope John Paul II to Mitch Lechelt, a former American Airlines pilot turned country-music writer, who leads off his CD “Open Doors” with a thank you to God for inviting him on an incredible trip? Is it the discovery of different talents revealed in some people like former Mr. America Larry Powers, who today mentors and encourages fellow Parkinsonians?

What does it mean to be a Parkinsonian? Well, it means being honest with yourself and your loved ones — facing the truth of your diagnosis and prognosis. It means being brave — dipping deep within yourself for the inner strength to meet the demands of each day at the highest level you can. It means being humble — accepting the help of your physicians, your family and friends, and organizations like APDA, who want to support you and make your life as full as possible. It means being hopeful — knowing that if you must have PD, this is the best time to have it, as science understands more about the disease than ever before and is closer to finding a cure.

And, to many Parkinsonians, it means being thankful.

Sincerely,

Vincent N. Gattullo
President

Stem Cell Research *continued from page 1*

the study, transplants improved the “off” state to about 60 percent of the best effects of L-DOPA, meaning that severe “offs” could be abolished. Some people were able to discontinue their L-DOPA because the transplant produced all the dopamine needed to move.

Some transplant patients have had dyskinesias even after stopping L-DOPA. In each case, these people had L-DOPA-induced dyskinesias for many years before the transplant. To control the dyskinesias, a few of these patients have had deep brain stimulators implanted in the same way as many patients who have never had transplants. It is possible that transplants done earlier in the course of Parkinson’s disease could prevent dyskinesias caused by L-DOPA treatment.

Because it is extremely difficult to recover fetal tissue appropriate to transplant into people, very few patients have received such transplants. Over the past 16 years in Colorado, we have operated on 61 people, the largest number of any center in the world. Colleagues in Sweden have operated on about 20 patients over the same time period, and a group at the University of South Florida in Tampa have operated on 30. The total number worldwide is about 200. To have transplants become a predictable treatment for Parkinson’s disease, we need to be able to produce dopamine neurons in the laboratory.

Stem cells have received a great deal of attention in the media and among politicians. We all depend on stem cells to survive every day of our lives. Billions of our skin cells, our red and white blood cells, and the cells lining our intestines are replaced every day by stem cells that divide and produce daughter cells. Even our brain has stem cells that replace cells that maintain our sense of smell and our memory. In case of accident or stroke, brain stem cells help repair the damage.

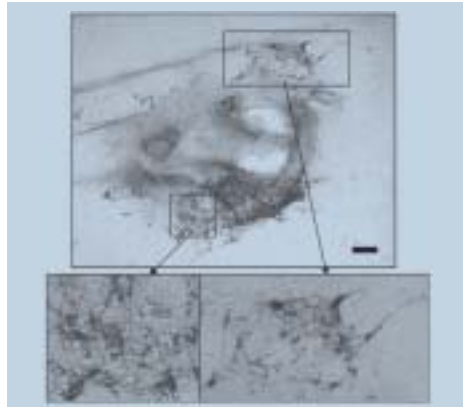


Figure 1. Microscope images of human embryonic stem cells that have become dopamine nerve cells after four weeks in tissue culture. The dopamine cells are stained black. The closeup pictures below the main figure show round and triangular-shaped cells with fine connections to other nerve cells.

Unfortunately, the brain is not able to replace dopamine cells in Parkinson’s disease. For that we must turn to human embryonic stem cells which we can grow in a tissue culture dish and which we then try to convert to any cell in the body under the right conditions.

With the help of a grant from the APDA, we have already had a good deal of success converting human embryonic stem cells into dopamine neurons. Using chemical factors that are known to guide stem cells to become dopamine cells during nor-

mal human development, we have found that embryonic stem cells can gradually change their character over a period of about four weeks and turn into dopamine nerve cells. Figure 1. shows the cells we have produced.

Much remains to be done. We need to figure out how to make more of the cells switch to dopamine neurons. We need to be able to pull just dopamine cells out of the culture without other cells contaminating the process. We also need to show that these cells can be transplanted into an animal, such as a rat, and relieve a condition like Parkinson’s. The animal testing of fetal dopamine cells about 25 years ago paved the way for human transplants 16 years ago. If these steps continue to work successfully, dopamine cells produced from human stem cells will probably be transplanted into people in the next five years.

For those who would like to read more about transplantation, I have written a book for the general reader entitled “*Healing the Brain*” with Simon LeVay as coauthor. It is available at www.Amazon.com. We have also published scientific articles in the *New England Journal of Medicine* (March 8, 2001), in the *Proceedings of the National Academy of Sciences* (January 2002), and in the journal *Stem Cells* (September 2004). ■

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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: My husband has been getting more forgetful. He was diagnosed with PD two years ago. The medications make him sleepy. He is frequently confused. He sometimes says that he sees people in the living room during the night. He became agitated a few weeks ago and was not sure that I was his wife and did not know where he was. What is going on? What can be done to help him?

A: Your husband probably has diffuse Lewy body disease. This is a condition that is characterized by dementia with parkinsonism. The medications used to treat the slowness, rigidity, tremor and walking problems may also cause confusion and psychosis in these patients. He needs to take the least amount of immediate-release Sinemet® that he needs to move and take it during the waking day. He may concentrate better with Alzheimer's disease medications like Aricept®, Exelon®, Reminyl® or Namenda®. Finally, Seroquel® may help him to sleep and control the hallucinations and delusions. Unfortunately, this type of parkinsonism rapidly worsens over several years, and the patients may become rigid, slow and severely cognitively impaired.

Q: I am doing well, even though I have had PD for several years. The only problem is this cramp that I have during the night in my right foot. The toes seem to be pulling down. My doctor tried giving me more medication at bedtime, but all this does is keep me awake. What can I do?

A: You are having dystonic early-morning cramping. This is due to the low levels of medication that are present just before you begin the daily dosage regimen. There are many treatments, although the problem can be difficult to eradicate entirely. You could take a long-acting Sinemet or dopamine agonist at bedtime. You could add an anticholinergic medication like Artane® or a muscle relaxant like Klonopin®. A dose of Parcopa® (an orally dissolving rapidly acting form of Sinemet) in the morning or during the night may help. Botox® injections into the leg and foot may also help.

Q: I am getting stuck with my feet glued to the floor whenever I walk through a doorway or a crowd of people. This is usually present when my tremor appears. At other times when my medications work too much and I am jumpy and swaying, I also get frozen. I saw a television program about NPH. Is this what I have?

A: The syndrome of NPH, or normal pressure hydrocephalus, is due to enlarged ventricles (fluid) in the brain. Patients have incontinence and dementia plus a magnetic gait. This type of gait is different from a PD freezing gait in that the patient with NPH walks as if he is wearing metal boots on a magnetic floor. You are experiencing on-and-off freezing. The off-freezing occurs when you are too slow, and the on-freezing occurs whenever your medications are working too much. The medications must be adjusted in such a way as to decrease the severity and frequency of the off periods without making the dyskinesia worse. This is the job of a PD specialist and can be achieved by lowering the amount of Sinemet and raising the dopamine agonist strength, and/or substituting immediate-release Sinemet with long-acting Sinemet and Comtan®. ■



FYI EDITOR: K.G. Whitford

WINTER 2005 VOLUME XII NO. I

F.Y.I. is an informational 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 PWP and their caregivers across the United States.

Connecticut Chapter Celebrates Its 20th Anniversary

While most Americans were planning for Thanksgiving last November, the Connecticut Chapter was celebrating its own Thanksgiving — the 20th anniversary of the Chapter's founding and the 15th anniversary of the Information & Referral (I&R) Center at the Hospital of St. Raphael in New Haven.

Though not the oldest Chapter, Connecticut's is in the senior league and is distinct in that it has been headed and guided by the same president since being granted its APDA charter on Nov. 18, 1984, Gladys Tiedemann. Much-honored for her volunteer work, Gladys was surprised when First Selectman Kevin J. Kopetz attended the anniversary celebration at the Aqua Turf Club to present her with an award from Governor M. Jodi Rell as well as a proclamation declaring "Gladys Tiedemann Day." She also was the East Haven Courier's featured "Person of the Week."

As part of the celebration, Gladys published "A Bit of History: American Parkinson Disease Association in Connecticut 1984-2004," a concise, well-written 12-page history of the Chapter and I&R Center from their beginnings as a support group in 1980 through the choice of APDA affiliation because of its commitment of grass roots support of the local Parkinson's community.

A cancer survivor herself and mother of six, Gladys was her husband's caregiver during his 18-year



Donna Diaz, left, and Gladys Tiedemann celebrate their respective milestones in APDA service.

battle with PD, giving her a first-hand affinity for the role of caregiver. (Hank Tiedemann was diagnosed in 1976 at age 47, survived five bouts with pneumonia and died after choking on a piece of grapefruit at age 65.) Before her

APDA work, she was an elementary-school teacher.

Donna Diaz, RN, also has the distinction of having headed her position since its inception at the Hospital of St. Raphael. Donna accepted the post after the Center at Yale University Hospital closed in 1989 and has been working closely with Gladys, the chapter and other New England Chapters and Centers since.

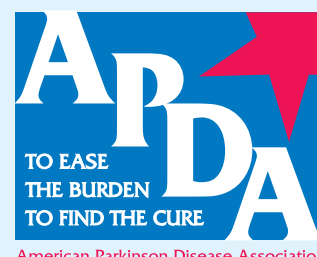
Congratulations, too, to the Massachusetts Chapter, celebrating its 20th anniversary this year, and welcome to Kern County Chapter, Bakersfield, CA, and Iowa Chapter, Des Moines, which recently received their charters. ■

APDA Introduces Its New Logo

Meet the American Parkinson Disease Association, Inc.'s new logo.

Designed by the Reno, NV award-winning graphics design firm Danaher Design, LLC, this logo uses a modern treatment with an abstract star to magnify the idea of "reaching for the stars" with respect to APDA's goal of finding a cure. The star and the colors, red white and blue, serve as a strong graphic reminder that the organization is the American Parkinson Disease Association, which distinguishes it from similar organizations. The tag line, "To Ease the Burden — To Find the Cure" is an integral part of the logo's signature.

A new logo was first considered two years ago and recommended by the executive committee of the board of directors. A survey of Chapters and I&R Centers affirmed the need for modernizing and defining the letters APDA, which were confused periodically with other organizations having the same letters such as the American Parliamentary Debating Association, the American Power Dispatchers Association and the Appliance Parts Distributors Association, not to mention several foreign-language Web sites. Unlike the previous logo, this one incorporates the organization's full name. ■



In the East

Organizing a walk-a-thon takes a lot of hard work and determination for anyone, but for Linda Jacoby in Mountaintop, PA, it was a challenge that would not be denied. Linda, a 57-year-old Parkinsonian and the youngest resident at Smith Health Care Ltd., said, "I don't want to just sit here and play bingo. I want to do something about it and something worthwhile," and she did! Her efforts contributed almost \$5,000 for Parkinson's research. Linda not only produced a hugely successful walk (the first of many, she promises), but also generated a great deal of publicity in the area.

In the West

The San Diego I&R Center's symposium for primary care physicians and other healthcare professionals was such a success that coordinator Ron Hendrix, PhD, reports that it is being considered for an annual event. The faculty included representatives from Loma Linda University, the Scripps Clinic, Coastal Neurological and the Neurology Center in Encinitas and Oceanside. Dr. Ron Kobayashi, a retired neurologist and movement order specialist, served as moderator. Dr. Hendrix noted that primary care physicians are the first medical professionals to deal with the diagnosis and treatment of PD, and the greater their knowledge, the better the care the patient will ultimately receive.

Dedicated Centers Address Needs for Specific Groups

APDA's 57 Information and Referral Centers across the United States are vital support vehicles for patients, their families and caregivers. Staffed with highly qualified, experienced professionals who work beyond their job descriptions to ease the burden of those in the Parkinson's community, they provide medical and quality-of-life information, support groups, opportunities for social interaction and, in some instances, respite care programs.

There are two Centers within the national network, however, with an added mission, to serve a specific population.

The Arlette Johnson APDA Young Parkinson's Information and Referral Center, Glenbrook, IL

Since the time it was identified as a specific disease, until just several years ago, PD was associated with people 60 years and older. In recent years, however, the age of the diagnosis commonly has become younger. Today, an estimated 10 percent of newly diagnosed patients are under 50 years old, and half of those under age 40.

APDA recognized this new population early and created The Arlette Johnson APDA Young Parkinson's Information & Referral Center at Glenbrook Hospital in Illinois, the nation's only young-onset Parkinson's disease I&R Center. Among the Center's free publications are "The Young Parkinson's Handbook: A Guide for Patients and Their Families," and a newsletter targeting the special psychosocial concerns of a younger audience. Its newly launched www.youngparkinsons.org is a welcoming Web site addressing a range of critical topics and age-related educational materials. There are also useful tips for daily living, materials specific to children, caregivers, parents and singles, and a page of poignant autobiographical sketches titled "Faces of Experience." The Center also encourages dedicated support groups throughout the country and groups are now functioning in more than a dozen states.

Susan Reese is the Center coordinator and can be reached at 800-223-9776 or parkinsonscenter@enh.org.

Armed Forces Veterans, Reno, NV

Any veteran, family member, doctor or other medical professional involved in PD treatment of veterans can contact the American Parkinson Disease Association I&R Center in Reno, NV, at 1-888-838-6456 for information about the disease.

Located in the Veterans Administration Medical Center, under the medical directorship of Dr. John Hollis Peacock, a former National Institutes of Health assistant surgeon the Center has actively pursued research about World War II veterans who served on the Pacific Island of Guam to help establish a link between the island and PD and other neurological diseases.

In addition to the research done at the Center, coordinator Susan Gulas provides traditional I&R support functions. ■

In the Southwest

TV and movie star Angie Harmon and her professional football star husband, Jason Sehorn, will be the honorary chairs for the 2005 Greer Garson Gala in Dallas in April. APDA's third vice president and former FYI editor Fred Greene reports that Angie, a local girl made good, is a Highland Park High School graduate who went on to be a Seventeen magazine cover girl and

has appeared on the TV series "Law and Order." Jason is an All Pro defensive back who has played for the New York Giants and St. Louis Rams.

In the South

Author, counselor and educator Dr. Marilyn Volker captivated her large audience for the South Florida Chapter and I&R Center and Broward Area Agency's collaborative presentation of "Relationships and

Intimacy" for individuals and couples coping with PD, Alzheimer's and stroke. Coordinator Gigi Gilcrease reports that Dr. Volker, who brought more than 30 years experience to her audience, "presented the topic with honor, humor and heart."

The Arkansas Chapter's spring seminar April 30, will be at Southern Arkansas University in Magnolia, about 15 miles from the Louisiana border. The Chapter is inviting all Pelican state residents to attend. Information is available from Lydia Stevens, 501-622-3990 or lsteves@htsp.mercy.net.

Executive Director Receives Award For Homeland Security Efforts

APDA executive director Joel Gerstel was among the members of the Transportation Security Administration's (TSA) Disability Coalition honored with a Friendship Award at a ceremony in Washington, DC, in December. The Administration is a division of the U.S. Department of Homeland Security.

He represents the Parkinson disease community on the 44-member coalition created to provide insight into the needs and concerns of persons with disabilities being screened at transportation checkpoints while meeting the stricter security codes introduced after 9/11. Rear Admiral David M. Stone, the Department's acting administrator praised the coalition for "being there when TSA needed you."

The presentation included a Friendship Award plaque and letter of appreciation. ■

New Book

How do certain people not only survive their travails but flourish in the face of them? And how do they persevere through pain and hardship, while the rest of us fret over things like a bad-hair day?

Those are the questions that Anthony Scelta, Jr., sets out to answer in his book, *Defying Despair: How One Man is Winning His Battle With Young Onset Parkinson's Disease*. He was a certified strength & conditioning specialist when, at age 25, he was diagnosed with PD. Scelta's formula is to feed the mind, train the body and nourish the soul.

The 157-page book published by Myson Publishing comes highly recommended by the author's friend, fellow Parkinsonian and former Mr. America, Larry Powers. ■

In the Midwest



Former Attorney General Janet Reno

The Midwest Chapter is busy preparing for its annual educational symposium with former attorney general Janet Reno and Michael Rezak, MD, PhD as guest speakers. It will take place Saturday, March 19, at the Oakbrook (IL) Marriott Hotel, and is open to people with Parkinson's disease, their families, and friends. More information is available by calling 847-724-7087 or online at cacapda@aol.com. ■

Mary Maral Mouradian, MD

APDA Scientific Advisory Board Member

Curiosity and then challenge — those were the motivators that brought Mary Maral Mouradian into medicine, then neurology, and now Parkinson's disease (PD) research.

"I chose medicine out of curiosity, to find out about the human body in health and disease. Then I became interested in the brain because of the complexities that it represents and how little we knew about it in 1982, when I decided to become a neurologist," she explains.

The William Dow Lovett Professor of Neurology and director of the Center for Neurodegenerative and Neuroimmunologic Diseases at the University of Medicine and Dentistry of New Jersey /Robert Wood Johnson Medical Center, is an APDA Scientific Advisory Board (SAB) member.

Her distinguished undergraduate and medical education at the American University of Beirut, Lebanon, and postdoctoral residency training in neurology at the University of Cincinnati Medical Center in Ohio, led to Dr. Mouradian's early association with the National Institutes of Health (NIH) in Bethesda, MD. Joining the NIH's National Institute of Neurological Disorders and Stroke (NINDS) as a visiting associate in its Experimental Therapeutics Branch in 1985, Dr. Mouradian rose quickly to chief of the Genetic Pharmacology Unit, a position she held for 13 years before accepting the Lovett appointment.

Lured in part by the institution's

outstanding work in Parkinson's disease — beginning with the pioneering work of its former department chairman, Dr. Roger Duvoison (and former SAB's chair) — she saw it as the opportunity to continue that tradition and enhance the research in neurodegenerative disorders.



Dr. Mouradian

As a clinician-scientist she is focusing on understanding the molecular determinants of basal ganglia function of PD. Her research studies the degeneration of brain cells that produce dopamine. "Now that we know that there are several genes involved in inherited forms of PD, we are investigating a number of these

gene products to see how they result in the death of dopamine — producing cells," she says. "We are currently able to treat only the symptoms but are encouraged in finding targets that can be tested for their potential to prolong the life of dopaminergic neurons, thereby slowing or even stopping the disease's progression."

It is difficult to believe that a scientist with such a driving mission, more than 170 scientific publications — including a book, active membership in five professional organizations, and two editorial positions, can also have a personal life, but she does.

Fortunately, she is married to a fellow neurologist who understands the time and energy she gives to her profession, and she shares her classical piano talent with her daughter, for whom she also functions as chief cheerleader at her tennis matches and soccer and basketball games. ■

M A I L B O X

Dear Agency Executive:

We are pleased to advise you that during the 2004 Employee Charitable Contribution Campaign, IBM employees and retirees pledged \$33,088 to your organization.

On behalf of IBM employees and retirees, we are pleased to provide this support and congratulate you for your outstanding efforts in the community.

M.D. Cooper
*IBM Employee Charitable
Contribution Campaign*

Dear Mr. Gattullo:

In a letter that I wrote to you about a year ago, I stated that my experiences with neurologists have not been happy ones. I had been diagnosed with Parkinson's disease in 1967 at the Marshfield Clinic. In the last year, I have received encouragement and help from many sources that you had recommended.

Cynthia Holmes (I&R coordinator at the University of Arizona) is foremost in my mind. She recommended a doctor at the University of Wisconsin, Madison, (Erwin B. Montgomery, Jr. MD) whom I saw for the first time on Monday of this week. I feel confident of the help he will give me. What encouraged me the most was a telephone call that she made to him the night before my appointment wishing me luck and good health. It's difficult to believe that this busy woman took the time to call about me — and it made me very happy.

Amy Schreiber
West Bend, WI

EXECUTIVE FUNCTIONS

By Carla Cothran, RN, MSN, MAEd, Coordinator, APDA I&R Center, Birmingham, AL

Thinking is sometimes impaired in Parkinson's disease (PD). The term "bradyphrenia" means slowed thinking, and this is a well-recognized phenomenon by patients, caregivers, and medical staff.

There is another thinking impairment in PD that is not so well known but is often the cause of much conflict between caregivers and patients.

Psychologists refer to this PD-related thinking impairment as "loss of executive functions." Neurologists often label this thinking impairment as the PD symptom apathy. Doctors and nurses may not even recognize "loss of executive functions" in their patients and become frustrated and puzzled by patients' behaviors and the conflicts between patients and caregivers.

Defining executive functions is not easy. Executive function refers to a diverse range of abilities that share the common feature of exerting higher-level control over behavior and adjust behavior in response to changing task requirements. Words (or thinking skills) that may be used to describe executive functions are: creative and abstract thought, planning, multi-tasking, sequencing, problem-solving, attention, concentration, and controlling short-term behavior to achieve long-term goals. Executive functions may also play a role in complex social behaviors such as being tactful or deceitful or adapting old skills to new or unique situations.

The loss of executive functions in the PD patient is often very subtle

and takes many months or years. Caregivers are usually the first to notice the changes in patient behavior that signal a loss of thinking ability. Social and community activities

will be stopped or avoided. If the patient is still employed, co-workers may notice a change in behavior at work. An example would be a female patient who recently reported that she was no longer able to be the chairman of a

committee at church. She was able to recognize in herself the inability to assess, evaluate, plan and implement. These are skills required to organize and motivate the committee to carry out its tasks. Another example is a male patient who reported he no longer was able to carry out tasks that took "more than an hour to complete". He said that if he thought the task would take over an hour, he would just not do it. This gradual

withdrawal from usual patterns of behavior and of day-to-day work in the world is very distressing to caregivers. In the past, doctors and nurses have told caregivers that the patient's social withdrawal was caused by embarrassment at being seen in public with tremors or with a slowed gait or postural instability. It seems, though, that this gradual withdrawal from social interaction and into the home

environment may also be due to the patient's loss of ability to cope with the constant bombardment of external stimuli from the outside world.

Recognizing that PD patients may feel threatened or anxious by tasks that require executive functions, thinking skills may be the most effective way of lessening caregiver/patient conflicts and doctor/patient frustrations. Nurses and doctors often say that a patient "doesn't hear anything that is said to him for the first 10 times in the clinic." This may be true because the patient is unable to process and problem-solve his way through large amounts of information at once. A good recommendation could be to write a simple list of activities, changes in medication or steps to perform a task during the day.

Caregivers are required to take over many physical tasks for patients, e.g. cooking or driving. This is a gradual process, and the skills required to physically care for a patient are not difficult to learn. However, taking over the thinking skills for a patient is a much more puzzling and frustrating caregiver

role. It seems to be unclear whether the current PD treatments are useful in preserving the executive functions in patients. Drug side effects such as hallucinations or obsessive/compulsive behaviors may compound the

problem. Perhaps just naming the loss and recognizing the problem will be of some help. ■



NEUROPROTECTION TRIALS IN PARKINSON'S DISEASE

By J.L. Juncos, MD, Medical Director
APDA I&R Center, Emory University, Atlanta, GA

The Neuroprotection Exploratory Trials in Parkinson's disease (PD), or NET-PD trials, are a series of clinical studies designed to examine new drug treatments that may slow disease progression in PD. Current treatments for PD help to alleviate and mask the progression of symptoms but ultimately fail to reverse the death of dopamine neurons in the brain. It is the loss of these neurons that is at the root of the symptoms in PD. In the last 10 years there has been an explosion of knowledge about the steps that lead to the demise of these neurons. From a genetic standpoint, rare mutations have been identified that lead to familial forms of PD. A few other mutations have been identified as risk factors that increased the vulnerability to PD in a larger number of patients who do not have a strong family history of the illness. All identified mutations have been linked to abnormalities in the processing or accumulation of a protein named alpha synuclein. This protein accumulates in damaged dopamine producing cells and other nerve cells leading to their death over time.

A better understanding of the steps involved in the death of dopamine neurons, and thus PD, has led to the discovery of compounds that may block this process at various levels. Examples of such compounds include drugs that help modulate energy metabolism in cells, drugs that provide or enhance the production of cell sustaining chemicals in the brain, anti-inflammatory agents, and drugs that block the action of chemical that may cause damage to cells. In fact research has led to the discovery of so many potential drugs that the

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Music Therapy

By Lillian Scenna, BS, LSW, APDA Maine Coordinator

Listening to music can be enjoyable and have many physical and emotional benefits as well. Studies show that the effect of music or "Music Therapy" can positively affect physical activities, emotions and even on memory.

Music Therapy definitely plays a role in a Parkinson's treatment program.

What is Music Therapy? According to the American Music Therapy Association... *"Music Therapy (MT) is an established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals. After assessing the strengths and needs of each client, the qualified music therapist provides the indicated treatment including creating, singing, moving to, and/or listening to music. Through musical involvement in the therapeutic context, clients' abilities are strengthened and transferred to other areas of their lives. Music Therapy also provides avenues for communication that can be helpful to those who find it difficult to express themselves with words. Research in Music Therapy supports its effectiveness in many areas such as, overall physical rehabilitation and facilitating movement, increasing people's motivation to become engaged in their treatment, providing emotional support for patients and their families, and providing an outlet for expression of feelings."*

A music therapist may work with a Parkinson's patient on goals such as walking, moving, synchronizing movements, improving balance, maintaining voice volume, increasing vocal projection and ability, and relaxing.

A group of scientists at Colorado State University Center and another group at Michigan's Center for Human Motor Research proved this theory. Participants were asked to walk both with and without listening to music. The results showed that people with Parkinson's disease could walk at a faster rate listening to music, and even were able to take longer steps. Walking with music also had a positive effect with overall balance and control. An article published in February 2001 by Tufts University Health & Nutrition Letter, stated, *"...based on these promising findings, some researchers have proposed that Music Therapy in combination with physical therapy should be the rule rather than the exception when treating those with Parkinson's..."*

Just how can simply listening to music have such a positive physical and emotional effect? One can speculate that music functions as a distraction from physical pain while doing certain tasks. Many have witnessed an improvement with Parkinson's tremors while listening and walking to a marching beat.

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Music Therapy *continued from page 10*

Moving musically can help with many typical Parkinson's problems such as freezing and difficulties in locomotion, including an improvement in the flow of speech. Above all, you can certainly depend on music to elevate spirits.

Across the country, many people with Parkinson's have already incorporated music therapy into their daily exercise routine. One therapeutic singing group is named the "Tremble Clefs." The group was founded in 1994 by a group in the Phoenix/Scottsdale area in Arizona as an adjunct program to voice therapy. This past summer, more than 30 members of the San Diego Tremble Clefs, led by Music Director Karen Hesley, SLP, provided enjoyable entertainment at the APDA National Coordinators Conference in San Diego. As one participant described... "singing has added many things. It helps the vocal cords and it is fun. And having fun is not always easy with Parkinson's."

Right here in Maine, Carl Barker, APDA State of Maine Chapter President, is well-known to countless groups and organizations for his demonstration of the benefits of harmonica playing.

Participants learn first-hand the therapeutic benefits with

voice and breathing control, while having fun learning and playing the harmonica.

For more information on Music Therapy, contact the American Music Therapy Association, Inc., 8455 Colesville Road, Suite 1000, Silver Spring, MD 20910 at 301-589-3300 or visit www.musictherapy.org.

To locate a music therapist in your area free of charge, send an e-mail to findMT@musictherapy.org. Please include your postal address with your request.

To learn about studies being conducted that use music to treat Parkinson's, Alzheimer's, stroke, autism, head trauma and other diseases and disorders, contact the Institute for Music and Neurologic Function, Beth Abraham Family of Health Services; 612 Allerton Avenue, Bronx, NY 10467, or visit its web site at www.bethabe.org. ■



FDA Approves Enablex for Treatment of Overactive Bladder

Novartis Pharmaceuticals Corporation announced the approval of Enablex® (darifenacin) extended release tablets for the treatment of overactive bladder (symptoms of urinary incontinence, urgency and frequency). Enablex, a once-daily medication, is expected to be launched in the U.S. in early 2005.

Enablex works by blocking the M3 receptor, which is primarily responsible for bladder muscle contraction. It is a potent muscarinic receptor antagonist that helps reduce

incontinence episodes, increases the amount of urine the bladder can hold, reduces the frequency of episodes, and decreases the pressure or urgency associated with the urge to urinate.

Full prescribing information are available at www.enablex.com or by contacting Kate O'Connor of Novartis Pharmaceuticals Corporation at (862) 778-5588 or via e-mail at kate.oconnor@pharma.novartis.com. ■

Neuroprotection

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National Institutes of Health and a group of Parkinson's disease investigators had to come together to devise a way to prioritize the study of these compounds based on an objective assessment of their potential. The result of this initiative is NET-PD, which is the most efficient and safest way to find the answers to these questions. So far, two such trials have been started. Creatine and minocycline (a tetracycline antibiotic) are being tested against placebo. Recruitment for this study has been completed, and the results are expected in another year.

A second study is still recruiting patients above age 30 with early disease who have yet to receive treatment. In this study, high doses of the dietary supplement Coenzyme Q10, and of a drug called GPI 1485 will be tested. Coenzyme Q10 protects cells by improving their energy metabolism. In doses smaller than the ones to be used, it showed promise in slowing the progression of PD. GPI 1485 may help damaged dopamine cells regenerate. This effect has been demonstrated in the laboratory and in animal models of PD.

Without the active participation of patients and their families, we will never be able to find out which of these drugs are safest and most effective in treating disease progression in PD. Unlike the symptomatic treatments we now have, protective treatments would be a far more effective way of managing the illness and avoiding many of its complications.

Recognizing the important role that patients have in this partnership of hope and discovery, we encourage those who qualify to find out more about the study by calling the National Institutes of Health at 1-800-352-9424, or logging on to the study Web page at www.parkinsontrial.org. or calling your local APDA I&R Center. ■

Information on Parkinson's Disease

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

EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**
4-page brochure (English, Chinese, Spanish)
2. **Parkinson's Disease Handbook**
Symptoms, causes, treatment; 40-page booklet (English, German, Italian, Portuguese, Spanish, Russian)
3. **PD "n" Me — Coping with Parkinson's disease;**
70-page booklet (English)
4. **Be Active — A suggested exercise program for people with Parkinson's disease;** 25-page booklet (English, German, Italian)
5. **Be Independent — Equipment and suggestions for daily living activities;** 32-page booklet (English, German, Italian, Spanish)
6. **Speaking Effectively — Speech and swallowing problems in Parkinson's disease,** 34-page booklet (English, Japanese)
7. **Good Nutrition 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 Has PD... But It's Okay!**
20-page booklet for young children.

EDUCATIONAL SUPPLEMENTS

Hospitalization; 34 Helpful Hints; Living Will; Helping Your Partner; Adapting to a Nursing Home; Comtan (Entacapone) The Treatment of Parkinson's Disease: Question and Answers; Comtan: Extending the Benefits of Levodopa; Comtan (Entacapone) Tablets and the Quality of Life in Patients with Parkinson's Disease; 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.

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 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

EXELON AND PARKINSON'S DISEASE

A new study published in the Dec. 9 issue of the New England Journal of Medicine indicates that the Alzheimer's disease medication Exelon® (rivastigmine tartrate — Novartis) was beneficial in treating symptoms of dementia in Parkinson's disease patients.

Patients treated with Exelon had better overall functioning and showed improvements in cognition and behavioral symptoms, compared to patients taking placebo.

This is the first large-scale, prospective, placebo-controlled study to demonstrate statistically significant cognitive benefits in Parkinson's disease patients having dementia. Patients also showed improvement in some important aspects of behavior.

The outcomes were better among patients treated with rivastigmine than among those treated with a placebo; however, the differences between these two groups were moderate and similar to those reported in trials of rivastigmine for Alzheimer's disease. The most frequent adverse effect was nausea. ■

The material contained herein concerning the research in the field of Parkinson's disease and answers to readers questions is 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.