

The American Parkinson Disease Association

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

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ADVANCES IN PARKINSON'S DISEASE RESEARCH

By M. Maral Mouradian, MD

William Dow Lovett Professor of Neurology

Director, Center for Neurodegenerative and Neuroimmunologic Diseases
 UMDNJ-Robert Wood Johnson Medical School, New Brunswick, NJ

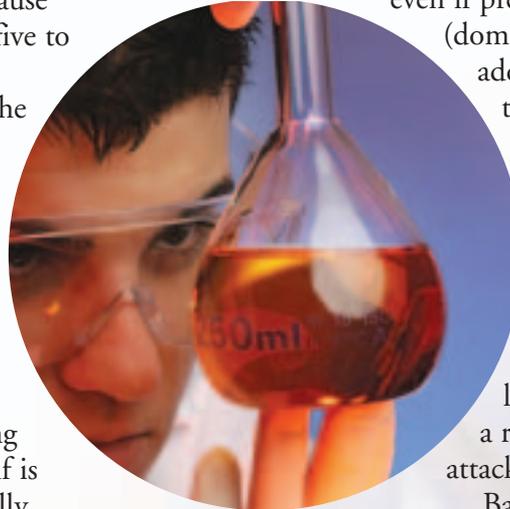
Most physicians and scientists agree that the major, irrefutable advance in Parkinson's disease research in the past eight years is the finding that a defective gene can cause this disease in some families. The second point is that we are not dealing with a single gene. Rather, multiple genes can cause Parkinson's disease, five to be precise, and counting. Further, the defects in each of these genes can be at different regions of the DNA in different families. The discovery of this multiplicity of genetic mutations is not entirely surprising since the disease itself is quite variable clinically, including its wide range of onset age, rate of progression and the predominant disabling symptoms.

The five Parkinson genes known to date are diverse in many respects including their localization in the human genome, their size, protein structure and function. Some of these are inherited in a dominant fashion, which means that if one parent is affected, 50% of the off-spring would be affected as well. Dominantly inherited Parkinson genes are alpha-synuclein and LRRK2/dardarin. Others are inherited recessively, which means that an affected individual must inherit two copies of the defective gene, one from each parent. The parents could be clinically normal because they each have only one copy of

the defective gene and one copy of the normal gene. Therefore, the parents are considered carriers but they do not manifest the disease. Recessively inherited Parkinson genes are Parkin, DJ-1 and PINK1. However, in some cases, parkin mutations can cause disease even if present as a single copy (dominantly inherited). In addition to these genes that are directly linked to Parkinson's disease, several other genetic variations in other genes are thought to represent susceptibility or risk factors for the disease, much like high cholesterol is a risk factor for heart attacks.

Based on taking history from patients, only about 20% of the cases admit having another family member with Parkinson's disease. Does it mean the remainder 80% does not have a genetic form of the disease, or is their disease due to an environmental factor? Intense research efforts are underway trying to address this question. But in the case of at least one of the five known Parkinson genes, LRRK2/dardarin, defects or mutations have been found in patients with no other affected family members. In addition, recessively inherited genetic defects can occur so infrequently in families that individual cases may not know of another affected relative and the disease can masquerade as "sporadic" or non-familial. This is particularly true if

cont. on pg. 10



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

Dear Reader:

Today's media are saturated with scientific and medical sound bites. In a recent National Public Radio interview Vincent Kiernan, a senior writer at the Chronicle of Higher Education, questioned the quality of scientific and medical stories because reporters and editors rushing for headlines run stories based upon initial findings in journals rather than on established results. Add to this the plethora of medical advertising on all media and it is easy to understand the general public's confusion.

Scientific research is an exact and tedious journey. The romanticized picture of a scientist working alone in a laboratory into the night and discovering a cure for some dreaded disease is now pure fiction. Hundreds of thousands of hours as well as millions of dollars are involved in the smallest step forward. Years may be spent on deciding if a fruit fly or zebra fish is a better model to use in a particular study.

APDA knows this first-hand because it has been a funding partner in every breakthrough in Parkinson's disease since its inception 45 years ago. That is also why we fund research on every level from summer internships giving medical students PD research experience to centers for advanced research.

This commitment to research is also the basis of our multi-year funding of centers for advanced research. Each center receives at least \$100,000 a year for five years based upon the progress of its work. Our Scientific Advisory Board voted in May to add two new centers, the University of Alabama and the University of Pittsburgh, to our network of six other centers at Boston University School of Medicine, Emory University School of Medicine,

UMDNJ-Robert Wood Johnson Medical School, UCLA School of Medicine, the University of Virginia Medical Center and Washington University Medical Center.

Most centers also host an APDA Information & Referral Center, providing seamless service from the most sophisticated research to day-to-day patient support and education. Referrals to physicians and services from our centers have helped people find the right means to accurate diagnosis, appropriate therapeutic plan and immediate support program, all in the same institution.



President Vincent Gattullo introduces the youngest attendee at the annual conference in Philadelphia last July. Charlotte Louise Weeks is the daughter of the Atlanta, Ga. Information & Referral Center coordinator Mary Louise Weeks.

Centers are selected for the number and quality of their research, the credentials of their team, the quality of their laboratories, and their patient-oriented research. Four APDA centers (UCLA, Mayo Clinic - Jacksonville, University of Virginia and University of Pittsburgh) are also National Institute of Neurological Disorders and Stroke Udall Centers of Excellence.

APDA is proud -- particularly in the present environment of low-priority government funding for scientific research -- of our strong, productive and growing network encouraging the work and dedication of the people and institutions that have provided the amelioration of suffering and will surely provide the cure for Parkinson's disease.

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

Vincent N. Gattullo
President

Matching Gifts

Many companies and corporations will match your tax-deductible gift and double or triple the amount contributed to continue the APDA mission "To Ease the Burden - To Find the Cure". Gifts can be in memory of a loved one or friend or to celebrate a special occasion. A card is sent to the designated person telling him or her of your generosity and thoughtfulness.

POWER OF ART AND MUSIC

By Sandra Frank, CSA

In order to benefit from the healing properties of art and music, it is essential to create a frustration free, nurturing environment that is conducive to experimentation.

As I present my programs in art and music to family caregivers and those with physical or psychological limitations, I observe an exciting transformation.

Wonderful changes take place. At first, skeptics approach me with comments about their physical disabilities or lack of talent. Although aware of their concerns, I reassure them that there are no grades in the class and I won't be sending any notes home. I tell them to just relax and enjoy the ride.

As the first session begins, the group is relatively quiet. Stress shows in facial expression and stiff posture. After a short period of time, the room begins to warm as the new artists are pleasantly surprised at their accomplishments. Those attending a music class join in by moving to the music or singing along. Lying dormant for perhaps years was the joy of artistic and musical expression. It is as if each person is waking from a deep sleep to face a stimulating new day.

For many years I taught watercolor painting to visually impaired and blind seniors. Many had never painted prior to their loss of vision and were over 80 years of age. Although willing to give it a try, many in the class were challenging me to make magic happen. It wasn't my doing, but theirs. After a few weeks, these new artists were looking forward to attending the next session. Although many couldn't see what they had produced, they would hold up their work and announce with a smile to the other participants that their work was superior.

Complaints about aches and pains were replaced by laughter and discussions about art and other interests. One of my students even said that her doctor told her he noticed a reduction in her blood pressure on days she attended class. As their self confidence increased, this group proudly entered their paintings into many art shows along with work produced by sighted seniors. Many in my class won awards over those with vision.

For others, music has healing powers similar to the visual arts. As I play the piano for those with Alzheimer's and Parkinson's disease and others in rehabilitation facilities, in addition to the mental stimulation I am aware that their stress is reduced as is depression and anxiety.

Detachment is replaced with smiles, singing and clapping. Participation is encouraged through the use of percussion instruments, music appreciation, sing-a-long and game playing. Everyone is happily surprised as just how much each knows about musical composition, composers and lyricists. As all the elements and musical theory come together, the groups will often compose their own piece of music. Sharing their delight with the others enhances socialization and improves communication and trust. Shy individuals start to feel comfortable shouting out the answers to questions about tunes from Broadway to Hollywood.

Both music and art can be appreciated in one of two ways, passively or actively. The passive appreciation of art and music can be achieved by attending exhibitions or concerts or reading about these art forms. Simply listening to a piece of music can have a calming influence, bring back happy memories or simply be a distraction from life's stresses. Similarly, using our sense of vision to enjoy an artist's work, look at old photographs and develop a greater awareness of our surroundings is a wonderful way to hold onto all those special gifts life has to offer.

Actively pursuing visual art and music adds another dimension to their healing powers. Participating in the creation of a work of art or a piece of music or increasing your knowledge of topics related to both art and music can enhance one's self-esteem and feelings of capability through mastery.

Art and music stimulate our minds and improve our memory. Using different media and learning to play a musical instrument are wonderful ways to increase mental energy and keep us alert. They are ideal ways to achieve "flow", or to be so involved in an activity that you wonder where the time went.

Music and art provide the two most important elements needed to promote lifelong feelings of well-being. These elements are distraction and purpose. Each helps remove us from our day to day worries, our focus on loss or on feelings of isolation. Artistic and musical expression can provide us with a sense of purpose. Whether we're painting a landscape or participating in an art show, listening to a symphony or singing in a choir, art and music are wonderful ways to encourage us to look forward to each day with a positive outlook. ■

Note: This article was originally published in the New Brunswick, NJ APDA I&R Center Winter 2006 Newsletter.



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 mother, age 79, was recently diagnosed with PD. Her symptoms consist of occasional minor hand shaking which she is able to control, stooped posture, shuffle in her walk and small handwriting, which remains clear and legible. Considering the bad side effects of Carbidopa/Levodopa medications, is there any real need for drug therapy at this stage?

A: Yes. Even a small dose of carbidopa/levodopa can prevent her from falling. You mentioned her posture is stooped and she takes small steps when walking. People do not die from Parkinson's disease, but from fall-related complications which occur as a consequence of the balance impairment associated with Parkinson's disease.

Q: My doctor has prescribed Azilect for me. The information provided says to stay on a low tyramine diet, which is confusing. It says not to take soy products, but every label of bread and crackers indicate they contain soy oil. One source says eating pizza is okay, while another says not to consume tomatoes - pizza has tomato sauce.

A: Rasagaline (Azilect®) is a stronger inhibitor of the enzyme monoamine-oxidase type B (MAO-B) than selegiline. There remains a possibility that foods rich in tyramine, certain antidepressants and narcotics and other medications may cause high blood pressure when taking a MAO-B inhibitor. In general, it is aged foods and liquids which are rich in tyramine. Your pharmacist and physician can provide you with a list of foods and medicines which could

Q: be dangerous. My father is 81 years old and was diagnosed in his 70's. The carbidopa/levodopa he takes makes him so nauseated that he often chooses not to take it. Has the Parkinson's patch been approved?

A: Nausea is the most common side effect of levodopa administration. That is why carbidopa is given with levodopa - to reduce the nausea and allow more levodopa to get across the blood-brain barrier. Sometimes giving a different preparation of levodopa-carbidopa such as Parcopa® which is absorbed on the tongue or a controlled-release levodopa-carbidopa tablet helps reduce the nausea. The rotigotine dopamine agonist patch should be available next year in the United States. But a word of caution regarding the patch- the levodopa and dopamine agonists produce nausea by stimulating an area of the brain which lies outside of the blood-brain barrier called the area postrema of the hypothalamus. The nausea is not produced by irritating the stomach. In other words any medication which either produces dopamine (like levodopa) or stimulates dopamine receptors (like the dopamine agonists) including rotigotine patch may produce nausea. The only medication which blocks the area postrema and does not cross the blood-barrier is doperidone, which is not available in the United States.

Q: My mother, 85 years old, has had Parkinson's for about 25 years and is now in the end stage. Both hands are tightly clenched and are painful. She is being cared for by hospice and no longer sees her movement disorder specialist. Her Sinemet® has been reduced quite a

bit. Is this hand problem due to the medication reduction? Is this a contracture or dystonia?

A: Many patients have had Parkinson's disease for over 25 years and are still functioning very well. I do want readers to think that this is how they will be in 25 years. That being said, your mother has dystonia and probable arthritis contributing to the hand contractures. Botulinum injections using type A (Botox) or type B (Myobloc) will help the painful contractures. Extra Sinemet may not help although dopamine agonists, muscle relaxants (clonazepam) and anticholinergics (trihexane) might help.

Q: My father has advancing Parkinson's disease. His greatest complaint is the inability to evacuate his bowels. He has been prescribed stool softeners without relief. He recently had an episode of transient global amnesia. One of the triggers for this episode could have been the Valsalva Manuever. Can you suggest any remedies regarding motility for their bowels?

A: For constipation eat lots of fruits, vegetables, salads, cereals and drink lots of water. Take a stool softener like docusate and a mild stimulant such as Senekot® every day. Take a strong orally administered laxative (if there is no bowel movement the next day) and you must work from below with enemas, suppositories and disimpaction if there is no bowel movement on the third day. Do all these things in consultation with your father's personal physician. Transient global amnesia may be due to vascular or electrical (seizure) causes and is not related to Parkinson's disease. ■



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

RICHARD H. MYERS, PHD

Member of the APDA Scientific Advisory Board and Accidental Neurogeneticist

He majored in French and psychology at the University of Kansas. Then he taught autistic children, which did pique his interest in neuroscience. It was, however, a job opening at Emory University in Atlanta, Ga., in a Huntington's disease (HD) research group that presented itself when he was a "poor struggling doctoral student" that hooked him on neurogenetics.

"Honestly, I didn't know anything about Huntington's disease, but this job paid better than my teaching assistantship," he confesses. Add regular visits to the laboratory by Marjorie Guthrie, whose husband -- folk musician Woody -- had died of HD, and her urging him to consider a career studying the disease. It was enough for him to begin taking every graduate genetics class that was available in the Atlanta academic community including those at Emory, Georgia Tech and Georgia State University.

In 1980, Dr. Richard Myers arrived at Boston University as an assistant professor of neurology at the School of Medicine as well as a lecturer at Harvard Medical School's department of neurology, where today he is a consultant in genetics.

On his arrival north, he began working with the team that 13 years later would clone the Huntington gene. Ironically a few days later, he received a telephone call from Drs.

Alice Lazzarini and Roger Duvoisin at Robert Wood Johnson Medical School in New Jersey, who were working on a project examining the possible role of genetics in Parkinson's disease.

"I was sort of looking around for other gene(s) to clone, so I organized the



Dr. Richard Myers is a success in the think tank or the swimming tank.

group that had cloned the HD gene and we initiated a study into potential genes for PD called the Gene PD Study." The group has been working on the project for eight years and has recruited the largest sample of familial PD to be studied - approximately 500 families. The group is particularly interested in possible gene interactions with pesticide exposure, and the possibility that several genes may interact to create a predisposal to PD.

Though a founding fellow of the American College of Medical Genetics, published more than 170 times in professional journals and author of 28 book chapters and non-refereed articles, Dr. Myers is not your stereotypical cloistered ivory-tower genius. For instance:

Athletics - He swims on a local Master's team three nights a week and is nationally ranked in the 200-yard breaststroke. He also swims the 200-yard individual medley, 100-yard butterfly, and "a couple other events. I enjoy the adrenaline that you feel when your are competing."

Music - He has had a long interest in blues guitar and with his wife of 28 years, Carol Anne, who was a keyboard major in undergraduate school, has played in several bands over the years. "That practice has done a number on my hearing, unfortunately, but I have been fortunate to play with some very talented musicians and I wouldn't trade that."

Not only do the Myerses make beautiful music together, but they also dance to it. After their younger daughter left for college, they took up ballroom dancing and are regulars at a local Fred Astaire studio. "We've really enjoyed foxtrot, tango, samba, cha-cha, rumba, and swing together."

Then, there's the 1963 Corvette Sting Ray (split window coupe) inherited from his mother-in-law. "It has been fun to keep it running and to tool around in that car on Sunday afternoons. It only gets about 12 miles to the gallon, but they didn't worry about mileage in those days, just speed, and it really does go! They don't make them like that anymore."

In the Northeast

Once a year chapter presidents and I&R coordinators from the northeast present the New England Regional Symposium, which is attended by hundreds of PD patients and their caregivers. This year the two-day event, titled "A Partnership for Progress," was held in Sturbridge, Maine. It included lectures, workshops, exhibits and a pre-conference program by award-winning folksinger Grace Griffith, who was diagnosed in 1998 with young onset PD and underwent deep brain stimulation surgery in March. Among the speakers were APDA I&R medical directors Robert Hamill, MD, (Vermont), Joseph Friedman, MD, (Rhode Island) and Marie Saint Halaire, MD, director of the APDA Center for Advanced Research at Boston University Medical Center. An inspirational dimension was added to this year's event with the creative works of artists from the New England Parkinson's community.

Maine's I&R coordinator Lillian Scenna reports that the third annual Mark Higgins Ride, though limited to one county this year rather the usual four counties, still raised \$1,200. Mark is a former master welder who was diagnosed at age 35 and was forced to give up his career as well as diving for sea scallops, "but has never given up on life," according to Lillian. "He rode his bike 80 miles a day from Presque Isle and finished in Patten, Maine in two days.

In the Southeast

Music therapy, the arts, and even therapeutic and recreational horseback riding were included in the West coast of Florida's "Parkinson's Disease Non-Motor Aspects and Thinking Outside the Box" symposium in October. In St. Petersburg, coordinator Faye Kern put together a full half-day event that also included a PD walker program by Julie Van-Vliet, executive director of The Gift of Sunshine, and her canine companion great dane Grandalf, "Breaking the Freeze."



The Circle Center Support Group of Richmond, Virginia, justly honored Ann Sprinks, center, for her 20 years of volunteer group leadership. Pictured with her are group members Donna Wright and Ron Kessler

In the Southwest

Former First Lady Rosalynn Carter was the featured speaker at APDA's Las Vegas seminar, Oct. 4. Mrs. Carter heads the Rosalynn Carter Institute for Caregiving, created in 1987 at Georgia Southwestern State University in Americus, and named in honor of its distinguished alumna. She concluded her talk with these words, "There are only four kinds of people in the world: those who have been caregivers; those who are currently caregivers; those who will be caregivers; and those who will need caregivers."



Las Vegas I&R Center coordinator Jeri Giallanza has a moment to pose with Rosalynn Carter following the former First Lady's address.

Two APDA Scientific Board Members Publish New PD Research

Dr. Ray Watts, neurology department chairman at the University of Alabama at Birmingham, was a co-author of a study published in the Archives of Neurology's September issue addressing a Parkinson's gene mutation and disease severity. APDA, the Department of Veterans Affairs, and an international coalition of pharmaceutical and governmental health organizations supported the study of the recently discovered LRRK2 gene.

Research showing that oxygen-free radicals are damaging proteins in the mitochondria and may be one cause of PD has been published by Dr. James Bennett, director of the University of Virginia's (UVA) Center for the Study of Neurodegenerative Diseases, with co-authors from the University of Oregon and UVA, in the 10th edition of the Journal of Neuroscience.

Board Member Honored

APDA board member Michael Melnicke, a nursing home administrator, ambassador, and chaplain, received Peninsula Hospital Center's Outstanding Trustee Award on Oct. 28, during the Far Rockaway, N.Y. hospital's 99th anniversary ball. Among his many roles, Mr. Melnicke is the director of the New York and Federal Law Enforcement Foundations, and is an ambassador-at-large for the nation of Granada.

November Was a Month of Honors For SAB Chairman Wooten

Dr. G. Frederick Wooten, Mary Anderson Harrison Professor and Chairman of Neurology at the University of Virginia, and chairman of APDA's Scientific Advisory Board (SAB), last month added two major awards to his long list of honors last month.

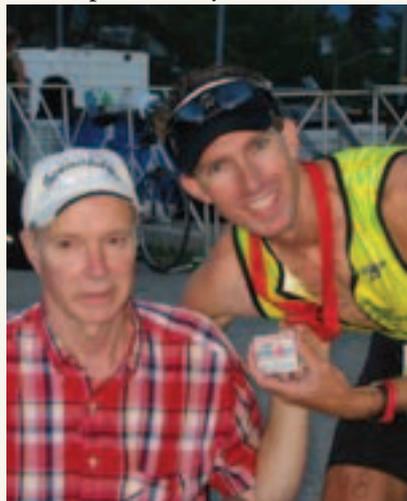
On Nov. 15, Robert Wood Johnson Medical School named him the recipient of its first Roger C. Duvoisin Visiting Professorship in Movement Disorders, at an awards dinner in New Brunswick, N.J. In his lecture, "Roger C. Duvoisin and the Quest for the Etiology of Parkinson's Disease," Dr. Wooten praised the founding chairman of Robert Wood Johnson's APDA Center for Advanced Research and former SAB chairman for his pioneering work in identifying a genetic link as a cause of PD.

At the APDA annual board of directors meeting four days later in Staten Island, NY, Dr. Wooten was presented the 2006 Fred Springer Award, established in memory of APDA's past president of more than 20 years. The award is given annually to a physician or scientist who has made a major contribution toward easing the burden and finding the cure for PD.

Dr. Wooten is chairman of APDA's Scientific Advisory Board.

Dallas Physician Honors His Father By Proving Himself An Ironman Befitting APDA's Work

Texas pulmonary and critical care fellow at Southwestern Medical Center, Dallas, Dr. Todd Hoopman, chose a



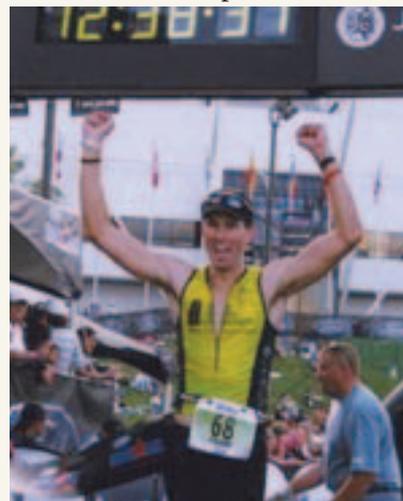
Todd with his inspiration, his father Dick, after the race.

challenging way to honor his father, Dick, who was diagnosed at age 40 with PD, 22 year ago and, according to his son, "chose to persevere and never give up hope for treatment improvements and a cure...."

Todd entered the Lake Placid (N.Y.) 2006 Ironman Triathlon with the ambitious goal of raising \$5,000. He completed the race, a 2.4 mile swim, 112 mile bike ride and 26.2 mile run within a 17-hour time limit, in 12.38 hours and raised close to \$15,000 for APDA's work.

Working with Janus Charity Challenge, an online fundraising program, Todd far exceeded his initial financial goal as well as bring honor to his proud dad. His detailed account of the race with photos is available

at www.quest4iron.blogspot.com ■



Todd Hoopman crosses the finish line.

APDA Participates in Udall Dinner

Dr. Stephen G. Reich, right, co-director of the University of Maryland Parkinson's Disease and Movement Disorder Center and medical director of APDA's Baltimore Information & Referral Center, received the 2006 Buddy Levenson Award for Enduring Spirit during the 13th annual Morris K. Udall Awards Dinner in Washington, D.C., in September. The event benefits the Parkinson's Action Network, the advocacy agency for PD.



APDA associate director for scientific and medical affairs, Michele Popadyneec, had an

opportunity to chat with Pennsylvania U.S. Senator Arlen Specter, left, after his spirited speech on the need for more federal funding for research. ■



Joel Miele, Jr. Elected To Board of Directors

Joel A. Miele, Jr., was elected to the engineering and planning firm An active member of his community, APDA board of directors during its founded in 1929. He is a graduate of Mr. Miele is also the past president annual meeting last month in Staten Polytechnic Institute of New York, and and director of the Kiwanis Club of Island, N.Y.

Mr. Miele, a professional civil organizations. He is a past president of the Broad Channel Athletic Club, co-engineer, is a partner in Miele the Queens County Chapter of the founder and vice president of the Associates, of Middle Village, Queens, New York Society of Professional Jamaica Bay Little League and member N.Y., an award-winning architectural, Engineers. of Community Board 10, Queens. ■

Why Consider Taking Part in a Clinical Trial?

RICHARD H. MYERS, PHD

(cont. from page 5)

Dr. Myers laments that neither of his two daughters, who are both in undergraduate school majoring in English, seems to have interest in basic science as a career, but he finds comfort in the possibility that, "perhaps they will write a great mystery novel, which includes forensic clues."

But, who knows. Look what happened with Dad who majored in French. ■

There is widespread agreement among physicians and people living with Parkinson's that clinical studies are necessary to find better treatments for Parkinson's disease (PD). In fact, recent surveys have shown that 80 percent of people with Parkinson's would participate in a clinical trial if one were available in their area.

Many people with Parkinson's, however, are not aware of the different types of clinical studies available. For example, often people do not know that while some studies test specific drugs, others focus on the potential benefits of exercise or the environmental and genetic links to PD.

No matter what type of study one chooses to be involved with, the experience can have many benefits. By participating in a clinical study you will:

- Increase your knowledge and understanding of PD and how it specifically affects you.

- Have access to leading healthcare professionals, quality care and potentially useful therapies.

- Personally contribute to accelerating development of treatments for PD.

In the words of Peggy Willocks, a person living with Parkinson's and clinical trial participant: "When I was first diagnosed with Parkinson's, I wanted to know everything about the disease that there was to know. Being in a clinical trial has put me in touch with those who are at the cutting edge of research in Parkinson's."

To learn more about clinical studies and review a nationwide list of trials by that are currently seeking participants visit www.PDtrials.org or call (800) 801-9484 for a free information kit.

APDA is a collaborating organization with PD trials to increase education and awareness about clinical research. ■

APDA I&R CENTERS COORDINATORS

By Cathy Thomas, RN, MSN, and Donna Diaz, RN, MS

The role of an APDA Information and Referral Center Coordinator is both rewarding and multi-faceted. Because of this, the 60 national APDA Coordinators have the unique opportunity to offer patients, families, health care professionals, and the general community access to the dynamic world of PD information and supportive services. In doing so, coordinators provide individuals with a better understanding of Parkinson's as well as strategies to effectively cope with the challenges presented by this disease.

APDA Coordinators come from a wide variety of backgrounds generally from within the traditional professions of nursing, health care, and social work. There are also many coordinators who also present impressive expertise in areas such as finance, public relations, academics, and community service. The experiences that coordinators bring to their APDA roles provide a solid complement to the responsibilities they take on at their individual Centers. Recognizing the need to provide novice coordinators with a standard yet personalized orientation to their position, the APDA, through a generous grant from The Medtronic Foundation, established a pilot project in 2004 to mentor newly hired coordinators. Cathy Thomas, RN, MSN (Boston, MA), and Donna Diaz, RN, MS (New Haven, CT), designed the Coordinator Orientation and Mentoring Program based on many years of collective experience managing their Centers in New England.

The program is administrated with

the cooperation and commitment of a number of people. Dr. Paul Maestrone and Michele Popadyne, RN, MPS, from the national office identify recently hired APDA Coordinators that are opening new centers or replacing outgoing coordinators. These orientees are mailed an APDA Coordinator Manual as well as other useful materials and are informed that an experienced coordinator/mentor will contact them to make plans to visit their centers. A pool of dedicated coordinator/mentors from various regions across the country has been selected to assist the new hires. The hands-on orientation process consists of a two day site-visit to the Centers by the mentors. Upon completion of the visits, the bond between the new hires and their mentors continues via phone calls, emails, meetings at national APDA conferences, etc. To date, 12 new coordinators have been mentored across the country.

The Coordinator Orientation and Mentoring Program offers new Information and Referral Center Coordinators the skills, tools, and professional camaraderie to become effective and successful practitioners. Through this project, the network of national coordinators is enhanced and strengthened. And, as a bonus outcome, ideas are exchanged, collaboration is promoted, and friendships are formed. As a result, all coordinators, working at the grass roots level, help further the APDA's mission "To Ease the Burden and Find the Cure" for Parkinson's disease. ■

Salvatore A. Esposito, Sr. Awards



At the 2006 Coordinator's Conference held in Philadelphia, PA the Salvatore A. Esposito, Sr. Awards were presented to the Information & Referral Center Coordinators, (left to right) Jean Baker (Burlington, VT), Paulette Olsen (Minneapolis, MN) and Lydia Skoog, (Great Falls, MT). The award is presented annually to coordinators in recognition of their contributions to APDA and efforts "to ease the burden" of the Parkinson's disease patients and their families. ■

MOBILITY FOR HANDICAPPED PATIENTS

Free Mobility For America, Inc. is a newly founded 501 (c) (3) organization dedicated to providing "FREE" Mobility Scooters and Power Wheel chairs to all Americans who suffer from walking difficulties and walking disabilities.

You can contact this organization at <http://freemobilityforamerica.com> or by phone at 1-800-313-8543 or by writing to:

Free Mobility For America
PO Box 5
Hound City, MO 64470

the disease gene manifests symptoms late in life, as is the case with Parkinson's disease. These observations suggest that even in the absence of positive family history for Parkinson's disease, a genetic defect can still be responsible for the disease in some cases.

Why are these advances important and why do we need to continue this line of research? We hope to get two main dividends from this research that would be of benefit to patients. First, discovering genes helps us understand what they normally do to brain cells and how their mutations result in nerve cell damage that underlies Parkinson's disease. Therefore, knowing these genes paves the way for numerous research directions to identify the detailed steps that begin with a mutation and culminate in the disease. This strategy is crucial for developing new drugs that target one or more of these steps with the goal of blocking or slowing down the spiraling events of nerve cell degeneration. As an example, knowing that excess alpha-synuclein accumulates in the brains of Parkinson patients and aggregates in an abnormal manner led to the recent testing of a vaccine to try to dissolve these clumps in laboratory mice. Such targeted therapy based on rational scientific principles carries many advantages. Even though each of the gene defects found to date appears to be responsible for a small minority of cases with Parkinson's disease, knowledge gained from these genes can give us valuable clues for the wider Parkinson population. This is because all these genes are functioning in the same group of brain cells and, therefore, even if

we can boost the function of one gene, it may still have an impact on the survival of these cells. Thinking farther into the future, when the time comes that we can identify the precise cause of Parkinson's disease in an individual patient, treatment can theoretically be targeted specifically towards that patient's underlying cause. Clearly, we are not at that stage yet, and current treatment decisions are not at all influenced by knowledge of an individual's genetic status.

The second dividend of gene discovery research in general is the testing of patients in order to



make precise genetic diagnoses and predictions. Testing for two of the known genes, parkin and PINK1, is now available through a commercial laboratory. Unfortunately, the multiplicity of the genes associated with the disease, the large number of separate mutations in a gene that can be linked to the disease, and the rarity of these genetic mutations (except for parkin which is mutated in 50% of cases with young onset recessively inherited Parkinson's disease), often make interpretation of genetic data difficult if not impossible. For example, a negative test of one even two genes neither excludes the diagnosis of

Parkinson's disease nor does it eliminate the risk of developing it in the future. In the case of parkin testing, finding a mutation in one of the two copies also makes interpretation difficult since cases of Parkinson's disease have been reported with only one copy mutation, even though most parkin mutations are recessive. Where genetic testing can be helpful at present is when a family is studied as a group, the gene responsible for their disease is either known or discovered in a research laboratory, then predictions can be made about individual family members.

Of course, such a situation should seriously consider ethical issues, whether or not an individual wants to know their gene testing result and how she/he would handle that information. With more research, only when these issues and complexities of genetic testing for Parkinson's disease are addressed satisfactorily, we can begin to consider presymptomatic genetic testing, i.e. testing individuals who might be at risk of developing the disease in the future. Such presymptomatic testing would be helpful for initiating preventive therapies if and when such preemptive measures become available. But for now, in the absence of such proven therapies and the difficulties of interpreting genetic results, wide spread genetic testing in clinics is not ready for prime time. ■

Note: This article appeared in the December 2005 - February 2006 Parkinson's Bulletin, The New Brunswick, NJ APDA I&R Center Newsletter.

Parkinson's Disease Stages

One of the first tools used to classify the clinical condition of a Parkinson patient has been the use of the **Hoen and Yahr scale**. This scale has five stages here listed:

- 1**
1. Signs and symptoms on one side only
 2. Symptoms mild
 3. Symptoms inconvenient but not disabling
 4. Usually presents with tremor of one limb
 5. Friends have noticed changes in posture, locomotion and facial expression

- 3**
1. Significant slowing of body movements
 2. Early impairment of equilibrium on walking or standing
 3. Generalized dysfunction that is moderately severe

- 4**
1. Severe symptoms
 2. Can still walk to a limited extent
 3. Rigidity and bradykinesia
 4. No longer able to live alone
 5. Tremor may be less than earlier stages

- 2**
1. Symptoms are bilateral
 2. Minimal disability
 3. Posture and gait affected

- 5**
1. Cachectic stage
 2. Invalidism complete
 3. Cannot stand or walk
 4. Requires constant nursing care

ARIZONA TELEMEDICINE

By Thomas Viviano, Coordinator APDA I&R Center, Phoenix, AZ

The Arizona Telemedicine system is comprised of 38 sites spread throughout the state equipped with two way cameras, televisions, and an enhanced sound system. Other similarly equipped "studios" are located within the prison system, and at behavioral health sites.

Some sites, like Banner Good Samaritan Medical Center in Phoenix, have multiple Telemedicine studios. In that facility, there is a large site within the main hospital tower; and there is also a camera in a conference room at the Comprehensive Neuroservices Clinic, where the APDA I&R Center office is located. The site is currently used for PD, ALS, and stroke consultations between patients and the neurologist specialists. The hospital hopes to expand the usage as the specialists and rural PCPs become more experience with this concept.

When doing a PD consult, Dr. Mahant or Dr. Samanta can control the camera at the rural site with a handheld

remote to zoom and focus on specific patient body parts to allow a better observation. They can also swivel the camera to watch the gait of a walking PD patient, or view another person in the room. Some sites have a nurse or medical assistant at the site during the consult; others have only someone to help the patient operate the equipment. The physicians may do 4-5 'remote' PD examinations in a morning.

Some advantages of telemedicine include the elimination of travel costs and provide time savings for the patient; and a reduction of anxiety in the patient or caregivers who are often uncomfortable driving in Phoenix or Tucson traffic. The Movement Disorder physicians in Tucson or Phoenix can offer their specialized services to a wider population of PD patients throughout the state of Arizona, where there are often large distances between medical facilities. ■

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. **Be Active** — A suggested exercise program for people with Parkinson's disease; 25-page booklet (English, German, Italian)
4. **Be Independent** — Equipment and suggestions for daily living activities; 32-page booklet (English, German, Italian, Spanish)
5. **Speaking Effectively** — Speech and swallowing problems in Parkinson's disease, 34-page booklet (English, Japanese)
6. **Good Nutrition**
20-page booklet (English), new edition
7. **Young Parkinson's Handbook**
78-page booklet (English)
8. **How to Start a Parkinson's Disease Support Group**
24-page booklet (English, Italian)
9. **Aquatic Exercise for Parkinson's Disease**
20-page booklet for patients and their families (English)
10. **Next Step After your Diagnosis** — Finding Information and Support
23-page booklet (English)
11. **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.wpd.org/ A weekly-updated source of world news.

A NEW REQUIP FORMULATION DECREASES "OFF" TIME IN PD PATIENTS

New data presented by EASE - PD (efficacy and safety evaluation in Parkinson's Disease) Adjunct Study® at the Annual European Federation of Neurological Societies Congress, shows that use of an investigational Requip (r) (ropinirole HCL) extended release tablet formulation to Parkinson's patients therapy delayed "off" time by an average of more than two hours per day when compared to placebo. The 24-week study, involved patients with Parkinson's disease not adequately controlled with levodopa (L-dopa). The extended-release form of Requip used in the study was a 24 hour dosage formulation not yet approved by the U.S. Food and Drug Administration. Requip, in its immediate-release (IR) formulation, is administered three times daily and has been shown to be effective in treating the motor symptoms of Parkinson's disease as monotherapy or in combination with L-dopa. GlaxoSmithKline conducted this study as part of the clinical development program for the investigational 24-hour extended-release tablet dosage formulation of Requip. The new formulation has been developed in collaboration with SkyePharma Plc. In the EASE-PD study, the most common adverse events reported were dyskinesia, nausea, dizziness, somnolence and hallucinations. ■

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.