

The American Parkinson Disease Association

F A L L 2 0 0 4 N E W S L E T T E R

The American Parkinson Disease Association

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

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THE BLANK CANVAS

By Elena Tuero, Freehold, NJ

I never knew I could paint. For me, it was a good day if I could just feed myself or take a few steps without falling. When you have Parkinson's disease, (PD) the idea of picking up a paintbrush is as remote as entering a figure-skating competition.

Now I paint constantly: landscapes, abstracts, still-life studies and my favorite — fat ballerinas. In all, I have completed more than 60 paintings in the few months since I started.

Some have remarked that I am making up for lost time, and that is certainly true. The last 17 years of my life have been spent in a losing battle with a disease that gradually stole my most basic capabilities, all during a time when I was struggling to raise two daughters as a single parent. Through the years I lost the ability to walk, talk or use my hands. I tried every known therapy for the treatment of Parkinson's, and when all of them failed I even tried suicide.

Last summer, at the age of 43, my life began again at Robert Wood Johnson University Hospital, thanks to a surgical procedure known as deep brain stimulation, which involves placing electrodes in the brain. With the activation of a pacemaker connected to the electrodes — literally the flick of a switch — I regained abilities I thought I had lost forever.

Helen Keller once wrote an essay titled "Three Days to See" in which she imagined what she would do if granted a brief interlude of sight. I have been granted an interlude to experience the full use of all our blessed faculties, but it is unknown

how long it will last. There is no cure for Parkinson's, and over time the beneficial effects of deep brain stimulation have been known to wear off.

And so I paint, while my hand remains steady and while there's still enough light. People say I'm pretty good at it. The only critics I try to please, however, are my daughters Tiffany, 14, and Vanessa, 13, and my lovely mother, Clara. Throughout their lives, the one image they had of their mother was one of sickness. Now when they bring friends by the house, they tell



them proudly, "My mother's an artist." That is all the praise I will ever need to hear.

One day recently I took a break from painting to clean my house, a chore I have been putting off for some time. Only those

who have suffered physical impairment can truly understand the sweetness of having their capabilities back. Few people, I imagine, can know the delight of mopping a floor as I do. The floor of my house is marked by numerous scratches, which are traces of my illness. I made them with my shoes while I was "kicking," a symptom of Parkinson's also called restless legs.

I am a little scared about what the future holds for me, but I am determined to cherish every second of my life.

Helen Keller ends her essay with an admonition to "use your eyes as if tomorrow you would be stricken blind."

To that I would add this thought: It is a privilege to be alive and in good health. Take time to appreciate the beauty of the morning, the shape of clouds and the embrace of those you love. ■

PARKINSON'S
CLINICAL TRIALS

Advancing Parkinson's Therapies is a community-wide initiative led by the major Parkinson's advocacy groups to accelerate the development of new treatments for Parkinson's.

Visit our web site if you would like to:

- **Learn more about trials that are seeking patients**
- **Receive regular updates by print and e-bulletin**
- **Obtain free educational brochures**

Visit the first-ever web site dedicated to Parkinson's clinical trials for more information.

www.PDtrials.org

This project is led by the Parkinson's Disease Foundation in collaboration with the following organizations: American Parkinson Disease Association, Parkinson's Action Network, Parkinson Alliance, The Michael J. Fox Foundation for Parkinson's Research, the National Parkinson Foundation and WE MOVE.



www.PDtrials.org



Dear Reader,

The holiday season always brings to my mind O. Henry's story of "The Gift of Magi."

If you remember, it is the tale of young newlyweds who are poor as can be but so very much in love that each wants to give a special Christmas gift to the other. Della, who has scrimped and saved every possible

penny, has \$1.87 and sells her prized chestnut brown hair to buy a platinum fob for her beloved Jim's gold watch. Jim, equally motivated, sells his watch, which had been his father's and grandfather's, to buy tortoise, jewel-rimmed combs for Della's cascading tresses.

Caregivers, you can well identify with Della's easy decision to sacrifice what she loved to give to the one she loved. You do it every day giving up your time, giving freely of your labor, and suppressing the emotions that are disturbing your sleep and invading your waking hours.

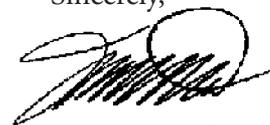
As president of the American Parkinson Disease Association, I find new dimension, to this well-known and loved story of reciprocal giving. Every time I get a letter such as the one from newly diagnosed Judy Williamson in Dallas, Texas, the "Ease the Burden," part of our APDA mission moves beyond words to action. "I realize that finding a cure through research is what we are all praying for, but "easing the burden is important as well," she says. (Judy's entire letter is printed in the FYI section of this newsletter.)

One in every eight Americans is a caregiver; eight of every eight caregivers are Dellas or Jims. They know that their care is costing them physically and emotionally, but it is worth it all. They can't even share their feelings with others because it is so individual and private, so grueling yet so rewarding. They live on hope.

I have heard many well-meaning people say, "I would like to put us out of business, to find the cure." Well, finding the cure is, of course, our mission's other function. But, if a cure were found tomorrow, we would still need caregivers.

I don't know if William Sidney Porter (O. Henry) was a caregiver, but he certainly captured the essence of the gift of giving in the final paragraph of his classic: *"The Magi, as you know, were wise men — wonderfully wise men — who brought gifts to the Babe in the manger. They invented the art of giving Christmas presents. Being wise, their gifts were no doubt wise ones, possibly bearing the privilege of exchange in case of duplication. And here I have lamely related to you the uneventful chronicle of two foolish children in a flat who most unwisely sacrificed for each other the greatest treasures of their house. But in a last word to the wise of these days let it be said that of all who give gifts these two were the wisest. Of all who give and receive gifts, such as they are wisest. Everywhere they are wisest. They are the Magi."*

Sincerely,



Vincent N. Gattullo
President

DRIVING AND PD

Symptoms of Parkinson's disease (PD) can certainly affect one's ability to operate a motor vehicle. Whether a person is capable of safe driving depends on many factors: Does the person have sufficient visual acuity?

Can he/she sufficiently judge the speed of other vehicles in order to maintain the proper distance from the car ahead?

Are reflexes fast enough to respond to unexpected situations?

How does one know when it is time to give up driving?

This is a difficult decision to make for most people, and people with PD are no exception! Friends and family members may lose confidence in the person's ability to operate a motor vehicle. These concerns may be warranted or not and the driver may or may not agree. When a disagreement or uncertainty about one's ability to drive arises, the opinion of a third party is often sought. In many cases this third party is the driver's physician. In most cases, the physician can be very helpful in resolving issues related to driving, however, the physician's input on such matters is typically given as a "recommendation" rather than as a decree. Another third-party source is a professional driving instructor. Having the driver evaluated by such a professional is a

good, unbiased way to assess the driver's ability.

Many people with PD remain safe drivers long after the diagnosis is made. Having PD does not mean that one can no longer drive. Still, the driver with PD needs to consider several things. If and when driving skills become impaired, going behind the wheel can put not only the driver, but also others, in danger. In the event of an accident with another vehicle, it may become difficult to disprove legal liability, and this could result in devastating financial consequences.

Each of us needs to make an honest assessment of his/her ability to drive safely. For more information about license renewal or other driving related issues call your local DMV office. For a useful Web site that addresses issues with driving visit <http://www.thehartford.com/talkwithholderdrivers/>

As always the APDA Parkinson's Information & Referral Centers are available to assist with information about Parkinson's related driving issues and how to access transportation resources offered throughout the various states. ■

This article was originally published in the Summer 2004 Parkinson's pages of the APDA Maine I&R Center.

EMBRYONIC STEM CELL RESEARCH APPROVED IN CANADA

The Summer 2004 edition of the Parkinson Post, a quarterly magazine of the Parkinson Society of Canada, announces that Bill C-6, An Act Respecting Assisted Human Reproduction and Related Research, received Royal Assent on Monday, March 29, 2004 and became law. This gives Canada one of the most comprehensive legislative frameworks in the world regarding assisted human reproduction.

The law is far-reaching and covers many areas, including the regulation of fertility treatments, but the relevance to people living with Parkinson's is that the law allows embryonic stem cell research to proceed in Canada under certain restrictions.

Many people in the Parkinson community have been closely following this Act over the past few years, as many scientists consider embryonic stem cell research to be a very promising area of research.

A government-appointed agency, the Assisted Human Reproduction Agency of Canada, will be established to license, inspect and enforce activities controlled under the Act. This Agency will apply safeguards and will have the authority to approve the use of embryos leftover from fertility clinics for stem cell research. The Act prohibits, among other things, human cloning and the use of reproductive material without consent. ■



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: Any new ideas concerning the cause of PD?

A: PD is associated with the loss of cells in the substantia nigra that make dopamine and the eventual death of areas of the brain which requires dopamine. Dopamine is manufactured in the cell body and transported by a protein called alpha-synuclein to the axon where it is released to other areas of the brain. In PD, as a consequence of abnormal genetics (poor construction and regulation) and environmental stress, the alpha-synuclein clumps upon itself. The transport system between the cell body and the axon malfunctions. This leads to a build-up of dopamine in the cell body, which forms free radicals and eventually kills the cell. At the same time this is happening, areas of the brain, which require dopamine degenerate, leading to dementia and balance impairment.

Research is under way to reverse this process and hopefully lead to a real treatment for PD. In the meantime, medical management — consisting of dopamine agonist therapy (which stimulates areas of the brain that require dopamine), selegiline/rasagiline (which decreases the formation of free radicals), co-enzyme Q10 (which boosts up energy transmission and keeps the cells alive

longer) and keeping the L-Dopa therapy as low and smooth as possible will treat the symptoms and slow down the disease progression.

Q: No one ever comments about sexual function in PD. What causes my erection difficulty? My desire for sexual relations with my wife is usually healthy but sometimes lacking. What can be done to enhance my sexual performance and desire?

A: Almost all of the medications used to treat PD can make it difficult to achieve an erection. Medications which decrease erection are those that block the parasympathetic system — most notably Artane, Cogentin, Kemedrine and Symmetrel. However, other medications which enhance the sympathetic nervous system such L-Dopa and the dopamine agonists can also make erections difficult to achieve and maintain. I often suggest the use of Viagra, Levitra or Cialis to help men to achieve an erection and Mirapex or Requip in order to increase libido.

Q: I often awake during the early morning with thick secretions in my throat which make it difficult to breathe. If I nap during the day,

I drool saliva. Is drooling related to these secretions? What can I do to decrease drooling?

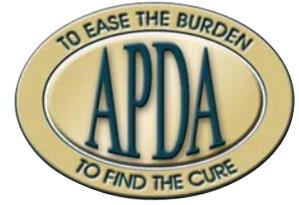
A: Robinul is helpful in reducing secretions and will decrease the drooling and the thick secretions.

Q: I often get hot flashes and sweat during the day. This occurs when my tremor returns. It seems this happens when I take my medication for PD. Is the medicine causing these symptoms?

A: You are describing the onset of an “off” period at which time the previous dose of your medications has worn off before the next dose starts working. A new form of L-Dopa called Pardopa is dissolvable on your tongue and works faster than Sinemet. This could be used instead of immediate-release Sinemet. In addition, attempts to lengthen the duration of the effect of your medications can be done using Sinemet CR, Comtan, Tasmar, dopamine agonists and reducing the time between doses. In the near future, a dopamine agonist patch will be available to provide a continuous release of medication. ■



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.



FYI EDITOR: K.G. Whitford

FALL 2004

VOLUME XI NO. IV

THE HON. LANE EVANS: Congressman/Parkinsonian

In the midst of the country's heated presidential race, Illinois's 17th Congressional District race was not a major political topic preceding Election Day, but Lane Evans, 53-year-old lawyer, Vietnam veteran, 11-term U.S. Congressman and Parkinsonian, was fighting for his political life.

Congressman Evans remembers the shock of experiencing difficulty in waving his hand in a parade in 1996, and even greater shock to discover that at age 45 he had the "old person's" Parkinson's disease.

For the next eight years he continued in the office to which he was

first elected in 1982. In the U.S. House of Representatives, he was a recognized leading advocate of veterans, becoming the ranking Democratic member of the House Veteran's Affairs Committee. Also a leading environmentalist, he was named an Environmental Hero by the League of Conservation Voters, and awarded the Conservationist of the Year Award in 1995 by the Heart of Illinois Sierra Club. All the time he was fighting off challengers as elections came and went.

During this election, however, his opponent, a former television news anchor, cited his "declining



Photo by John Schultz/Quad-City Times

Lane Evans celebrates his 12th term election to the U.S. House of Representatives.

APDA Expands and Adds to Its Internet Site

A collaborative project by APDA and WE MOVE, Inc. is making updated, comprehensive, Web-based information instantly available to patients, caregivers and physicians, and a new Young-Onset site has been launched by the APDA Young Parkinson's Information and Referral Center in Illinois, www.youngparkinsons.org.

The program, PD News & Updates, is the first menu option on the national Web site, and is composed of three pages:

- PD News Articles provides timely information about cutting-edge research and treatment options
- Patient Information, comprises detailed, original patient-directed content about PD symptoms, etiology, epidemiology, pathophysiology, diagnosis and approaches to treatment along with an interactive, online glossary
- Information and resources for healthcare professionals includes comprehensive Web-based information about the disease, case-based learning modules in WE MOVE's Movement Disorder Virtual University, a teaching slide set for use by nurses and the WE-MOVE PD news service.

The Young Parkinson's site addresses a range of critical topics including a page of poignant autobiographical sketches titled Faces of Experience about younger diagnosed patients. The site abounds with age-specific educational materials, useful tips for daily living, and contains materials specific to children, caregivers, parents and singles.

health," as a campaign issue.

When a Peoria (Ill.) Journal Star reporter asked APDA executive director Joel Gerstel to comment, he answered, "Individuals with Parkinson's are usually well aware of their physical limitations and would know better than an outside observer if they should quit a job or activity."

When the Associated Press called later that week, Gerstel used it as an opportunity to make a statement for all Parkinsonians, citing individuals such as former Attorney General Janet Reno, Pope John Paul II, and actor Michael J. Fox. Gerstel said, "to be using it as a campaign issue is ridiculous."

Though the Rock Island legislator admitted that some days were more difficult than others, he was convinced that he was fit for the job and buoyed by the outpouring of support, waged a vigorous campaign.

On Tuesday, Nov. 2, Lane Evans handily defeated Andrea Zinga, and was re-elected to serve his 12th term in the House of Representatives. ■

In the West

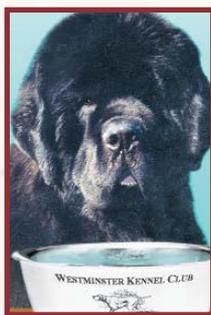
Casino Carnivale, an outdoor Mardi Gras and Carnivale-theme fundraiser, brought out more than 100 of Los Angeles's "A List" invitees as well as an impressive roster of corporate contributors including Universal Studios, Warner Brothers, NBC, Hilton Hotels and American Airlines. The event was sponsored by the APDA West Coast Office.

In the East

The New England Chapters' October symposium began with PD 101, led by Dr. Marie St. Hillaire, director of Boston University Medical Center's Movement Disorder Program. Coordinators and chapter representatives from Vermont, Connecticut, Rhode Island, Maine and Massachusetts prepared a two-day schedule of lectures, workshops, exhibits and networking opportunities on topics including deep brain stimulation; behavior, mood and thinking; caregiving; medication management, and complimentary therapy.

The Salvatore and Elena

Esposito Chapter (Staten Island) joined with NY S.A.V.E., a not-for-profit organization providing free emergency veterinary care for low-income New



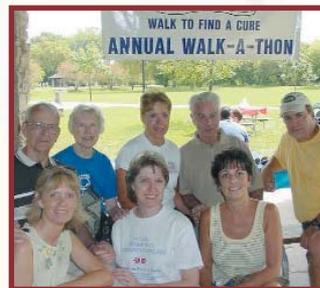
Pooches for Parkinson's stars Josh and Barney

Yorkers, for its first Pooches for Parkinson's Walk. The Columbus Day oceanfront walk and fun dog show was led by Josh, the 2003 Westminster Kennel Club best-in-show winner, and Barney, a local paraplegic golden retriever.

It took Ron Brown, a 36-year-old volunteer firefighter, 58 hours and 40 minutes to break the world record for marathon bowling, enter the Guinness World Book of Records and benefit the **Pittsburgh Chapter** in honor of his dad, Alvin Brown, who was diagnosed eight years ago. For the statistically minded, Ron bowled 362 games taking only one 15-minute break to show-

er and use the facilities every eight hours, broke two bowling balls in the process, and threw about 7,000 times — 21 tons.

In the Midwest



Young Onset Parkinsonian Jan Quist, top row center, author of "My Mommy Has PD But It's Okay," took along her family to the Midwest Chapter walkathon in September.

COORDINATORS GO WEST

The annual conference of APDA coordinators moved to the West Coast in August, attracting more than 50 participants to San Diego for two days of educational lectures, programs, awards, networking and socials.

Coordinators from Maine to hosting San Diego attended lectures by Dee Silver, MD, and Kathryn Ely, PhD, on new drugs/neuroprotection, and cloning, stem

cell and gene therapy. Dr. Silver is a movement disorder specialist, and Dr. Ely is a professor and director of scientific advancement at The Burnham Institute, San Diego.

Participating coordinators shared successful new programs: "A Good Start — A Program for the Newly Diagnosed Patient," by host coordinator Ron Hendrix, PhD, and "Power Over Parkinson's — A Wellness Program," by Cynthia Holmes, PhD, Tucson, Ariz. coordinator. New Haven

coordinator Donna Diaz, RN, MS, moderated an afternoon session giving participants an opportunity to introduce themselves, identify specific strengths and capabilities they bring to their role as APDA coordinators, and hear the organiza-

tional goals and objectives from the national office staff.

A highlight of the conference was the opening dinner's entertainment by Tremble



President Vincent Gattullo with 2004 Salvatore A. Esposito, Sr. Award winners Susan Daniels, Barbara Warren and Lillian Scenna.

Clefs, a performing musical ensemble of more than 60 people in various stages of PD. It began as a voice-therapy group and is now in demand for its shows.

Three coordinators received the Salvatore A. Esposito, Sr. Awards during the farewell reception and dinner in recognition of their service and contributions to APDA. President Vincent N. Gattullo presented plaques and awards to Susan Daniels (California), Lillian Scenna (Maine) and Barbara Warren (North Carolina). ■

Who would think that sand volleyball could be an historic largest single Parkinson fundraiser? The employees at the Weitz Company did! **Nebraska Chapter** President Mary Eggers reports more than \$16,000 was raised in its second year, topping last year's \$15,920.

In the South

If the ladies of Atlanta look particularly fashionable, they probably attended the **Georgia Chapter's** fashion show benefiting its very successful respite program that began with an anonymous private donation seven years ago and is the state's only Parkinson's respite program.

Coordinator Lydia Stevens reports that the **Arkansas Chapter and I&R Center** put together a full day of learning for the 200 people who attended their Fall 2004 Parkinson Disease Seminar at the Baptist Medical Center. Among the topics were the pharmacology of current treatments, the importance of exercise and the benefits of music therapy.

St. Petersburg's coordinator Faye

Kern reports that a tree was planted in memory of Barbara Brown, who succumbed to cancer in 2003. Barbara was the **Pompano Beach** coordinator for four years and recipient of the Salvatore A. Esposito, Sr. Award.

In the Southwest

President Bob Dunagan reports a busy fall for the **New Mexico Chapter**. It was judged Best Table Display of the 48 organizations participating in the Combined Federal Campaign Kick-Off at VA Hospital in Albuquerque, and participated in a CFC presentation at Kirtland AFB in September followed by participation at Health Fairs for State Employees and at the State Capital and the Navajo Regional Office in October.

Amy Haralson, a Young Onset patient, has succeeded Bill Erwin as

president of the **Brazos Valley (Texas) Chapter**. Bill founded the chapter in 1998, has been named president emeritus, and will continue his longtime service to Parkinsonians and APDA.

TV producer and deep brain stimulation spokesperson Ray Farkas was the **Northeast Texas (Dallas) Chapter's** featured speaker at its September symposium, "Parkinson's Disease Technology and Caring in the 21st Century." More than 200 people heard Farkas, who has appeared on "Nightline," CNN and Oprah and is completing work on a documentary and full-length film about his surgery. A non-technical highlight



Fred Greene, left, with Judy Williamson and Marie and Don Rontondi.

of the symposium was introducing the **Fred A. Greene Volunteer of the Year Award** named after the **Northeast Texas Chapter's** founder and **APDA** third vice

president. Don and Marie Rontondi were named the award's first recipients in honor of their selfless volunteer contributions. ■

GALAS GALORE

Honoring Troy and Ava Crowder In Lubbock, Texas



Ava and Troy Crowder are surrounded by their three generations including then 2-week-old great granddaughter Alexandra at a dinner honoring them sponsored by the West Texas Parkinsonism Society.

Spirit of Life Award Dinner In San Diego, California



Bill Stilwell and Dr. Dee Silver were honored by the Parkinson's Disease Association of San Diego. Larry Hunt presents Bill with his Award. With them are Joel Gerstel, second from right, and Dr. Ron Kobayashi.

G. Frederick Wooten, MD

Chairman, ADPA Scientific Advisory Board

The basis of APDA's annual \$2.5 million research awards is its Scientific Advisory Board chaired for the past seven years by G. Frederick Wooten, MD, professor and chairman of the University of Virginia (UVA) Health Sciences Center's Department of Neurology in Charlottesville.

Dr. Wooten, who was born in Alabama, began his academic career at Rice University in Houston, Texas, then headed north-east to earn his MD from Cornell University Medical College in New York City, where he would later return for a neurology residency and begin his faculty career as an instructor at New York Hospital-Cornell Medical Center. In between, he went to San Francisco for an internship in internal medicine at H.C. Moffitt-University of California Hospitals, and spent three years as a research associate postdoctoral fellow in Washington, D.C. at the National Institutes of Mental Health.

He joined the faculty of Washington University School of Medicine in St. Louis, Missouri, and five years later relocated to UVA, where he rose from professor of neurology to department chairman in less than a decade.

Dr. Wooten received his first research grant from APDA in 1978, and a George C. Cotzias Research Fellowship in 1979. Considering his future calling, both were most appropriate, but especially the latter because as a young medical student, the future neurologist met Dr.

Cotzias at the Brookhaven National Laboratories on Long Island.

"There I saw patients taking pills and getting up out of wheelchairs to walk. I have never gotten over the wonder of it," he recalls.



Dr. G. Frederick Wooten, Chairman, Scientific Advisory Board

Upon the recommendation of Dr. Roger C. Duvoisin, MD, chairman of APDA's Medical Advisory Board — renamed the Scientific Advisory Board (SAB) in 1995 to reflect its academic representation — Dr.

Wooten was named a board member in 1987. In 1994 he was named director of APDA's Advanced Center for Parkinson's Research at UVA and became the SAB chairman.

Dr. Wooten's 25-page curriculum vitae includes more than 100 academic publications, two pages of honors and awards, more than 50 invited lectures and 22 years of service to PD research and academia.

Away from the laboratory, Dr. Wooten is happy with a fishing rod in the Virginia mountain streams, farming or cheering on his favorite St. Louis Cardinals. But the role he loves best is grandfather. "I have two sons, two daughters and five grandchildren spread from Chicago to Nashville. I would feel incredibly fortunate to have any one of them, but to have all nine makes me the most fortunate person I know."

After an adult lifetime commitment to his specialty, G. Fredrick Wooten continues to harbor an almost little-boy excitement at discovery, the stuff that makes him one of today's recognized leaders in PD research. ■

M A I L B O X

Dear Paul: (Dr. Paul Maestroni, Director of Scientific & Medical Affairs)

I've just received the summer issue of the APDA newsletter and was thrilled to read the account of the Scientific Advisory Board. It made me proud to see that the SAB still functions essentially as it did when I retired from its chair seven long years ago! The list of grants and fellowship awards was most impressive. I note that the titles of the various funded research projects indicate that much progress has been achieved in the last seven years.

It's clear that research is much more focused on the basic biological mechanisms of PD today than was possible at the time I retired. That, of course, is in large part due to the discovery of the role of alpha synuclein in the Contursi kindred. As a researcher at the University of Pennsylvania recently commented, that discovery "blew the top off Parkinson's research." No doubt you'll remember that APDA played a large role in that!

Keep up the good work! Please convey my congratulations to all.

Roger C. Duvoisin, MD

Chapel Hill, North Carolina

(Former chairman of the Scientific Advisory Board and a pioneer in pinpointing the location of a gene responsible for PD.)

Dear Mr. Gattullo:

I was diagnosed one year ago with Parkinson's disease. I am writing to thank you from the bottom of my heart for creating the Information and Referral Centers. You have no idea what a difference the I&R Centers make in the lives of us living with Parkinson's disease.

I have first-hand knowledge of this by the help I have received. I also volunteer at the I&R Centers at Presbyterian Hospital here in Dallas, Texas. Through my volunteering, I am in contact with many patients as well as their families. It is a wonderful feeling to hear people express their appreciation for the help they receive.

I realize that finding a cure through research is what we are all praying for, but "Easing the Burden" is important as well.

The I&R Centers are APDA's connection to the people who are doing their best to live their best lives with Parkinson's.

Judy Williamson

Dallas, Texas

Exercise in Parkinson's Disease

Parkinson's disease (PD) is a complex neurological disorder that affects everyone differently. The good news is that there are many treatment options and changes in lifestyle that can help to better manage the disease – regardless of these differences. One of the options that may be beneficial is regular exercise, which can help maintain flexibility, promote good posture, keep muscles strong and joints supple. Mild to moderate exercise can improve circulation to the heart and lungs and it can also help deal with stress.

“Most people living with Parkinson's disease can improve their well-being by staying strong and flexible”, says

Jorge Juncos, MD, Associate Professor of Neurology, Emory University School of Medicine. Juncos adds, “It is important to remember that before starting any exercise program, you should check first with your doctor to make sure that the activity is right for you.”

These activities could include walking, swimming or even complementary therapies, such as the Alexander technique (a stretching technique that promotes muscle relaxation), yoga, or Tai Chi. These exercises focus on balance, flexibility and movement. A physical therapist can help determine which exercises are best suited to your condition.

Cate Morrill, Certified Instructor and Director, Rising Phoenix Tai Chi, offers tips for those planning a regular exercise program:

- Choose a time to exercise
- Be sure to stretch
- Work at your own pace
- Recognize when you are tired
- Move only to the point of resistance

- Remember to drink plenty of water

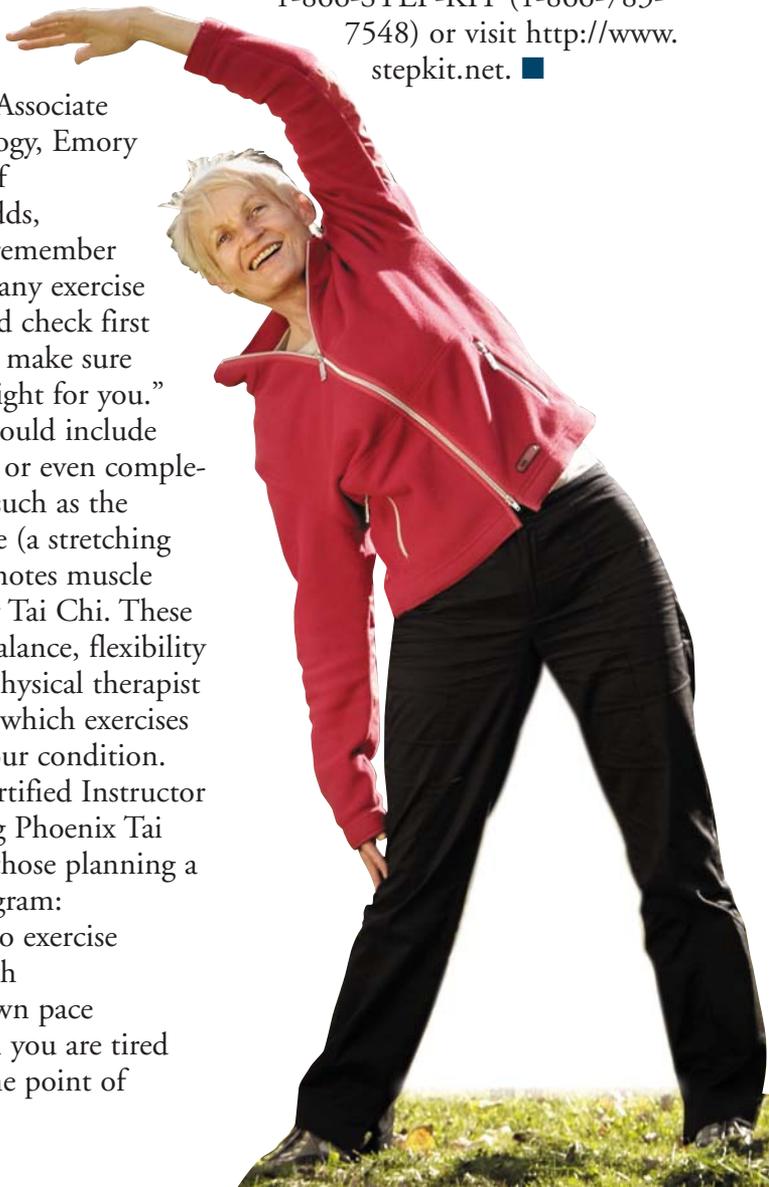
Since staying active is so important, the American Parkinson Disease Association, in conjunction with Novartis Pharmaceuticals Corporation, is pleased to offer a new, free information kit called StEP Kit. The “StEP Kit” features a 30-minute exercise video designed specially for people with Parkinson's disease. The kit includes treatment information, tips for caregivers, nutrition recommendations and suggestions for coping with the challenges of Parkinson's disease. To order a free StEP Kit, call toll-free 1-866-STEP-KIT (1-866-783-7548) or visit <http://www.stepkit.net>. ■



APDA/IBM STUDY UPDATE

The last edition of the Young Parkinson's (Summer 2004) newsletter reported on a study involving PD volunteers and IBM researchers on the effects of Parkinson's disease on computer usage, especially typing and mouse control. Study participants are providing recordings of their typing for analysis by the researchers. This feedback has already helped to improve the IBM program, which is being designed to reduce or eliminate many of the problems which plague computer users who have PD. When the current group has completed the testing, a second group will test the improved version of the program. A study of mouse usage is planned.

Early results from the typing samples are providing helpful information regarding what keyboard setting changes may be needed to make typing easier. If you have a suggestion for a change that would make your keyboard easier to use, or if you would like more information about the IBM studies, contact Shari Trewin by e-mail (trewin@us.ibm.com) or telephone (914) 784-7616. ■



PD & PREGNANCY

Pregnancy in Parkinson's disease (PD) is not a common event, nevertheless, it can and does happen. Very little information is available in the medical literature regarding this subject and as a consequence, health care professionals can offer little counsel to women with PD who are contemplating becoming pregnant or are already pregnant.

The American Parkinson Disease Association Young-Onset Information & Referral Center (Tel. 1-800-223-9776) is working in collaboration with a movement disorders specialist and a PD nurse specialist in the United Kingdom who have designed a questionnaire to acquire anecdotal histories from women who have experienced one or more pregnancies after being diagnosed with Parkinson's disease. As a result of this study, it is hoped that a fact sheet can be developed to enable women

with PD who wish to become pregnant to make more informed choices.

For more information or to request a questionnaire contact Mike Scott, Parkinson's Disease

Nurse Specialist, Medicine Level One, Conquest Hospital, St. Leonard's On Sea, East Sussex, UK TN37 7RD, telephone 0044 1424 755255 x 6432, e-mail: michael.scott@esht.nhs.uk ■



What's In a Name? Everything

More than 1.5 million people have been diagnosed with Parkinson's disease (PD) in the United States. Many of them have found ways to confront their diagnosis, acknowledge their frustrations and learn to cope with the illness by joining local support groups. Support groups empower individuals through education and provide an opportunity for sharing experiences with each other.

Thanks to the American Parkinson Disease Association, Inc. (APDA), Chapters, Information & Referral Centers, Support Groups and the volunteers of the Parkinson's community, many individuals have a place to share ideas, learn from each other's experiences, and most of all, have a safe place to laugh and to cry.

The APDA assists more than 1,000 support groups throughout the United States. The reasons people join support groups can range from getting answers to simple questions, to finding help in facing a major crisis. It is not easy to accept the diagnosis of a chronic illness such as Parkinson's disease. Many newly diagnosed people don't receive all the answers from their healthcare professionals, and they seek support groups for education, first-hand experience, advice and friendship. Support groups also work to increase awareness of Parkinson's disease by the general public.

Each support group carries its own personality and focus. Support groups can range in size from a few to as many as 35 to 50 people. Many support groups offer a variety of speakers and resources to their members. These programs typically will address caregiver and patient issues.

There are some people who hesitate to join a support groups. Perhaps they fear they will become depressed or anxious about seeing other more advanced cases of their same disease. Many newly diagnosed individuals are frightened and overwhelmed. It may help ease those fears to remember that no two individuals with



Parkinson's disease are alike.

Everyone progresses at a different rate and can manifest different symptoms. Many people who are advanced in the disease process find great satisfaction having an opportunity to share their experiences openly and what methods were helpful to them along the way.

Parkinson's disease affects the entire family. It is important to remember that anyone can attend a support group meeting. Friends and family members may find comfort in attending a support group, even if the individual with the disease chooses not to attend. Many times the person with Parkinson's goes to the group after someone close has attended a meeting or two and has found that the experience can be informative and helpful and not at all threatening.

For more information about Parkinson's disease and the support groups in your area, call the toll free number 1-(888) 400-APDA (2732) ■

FALLING AND PD

“*We have nothing to fear but fear itself.*” Roosevelt’s words have resonated into our lexicon, and are applicable to one of the major concerns of the infirmed and elderly: the fear of falling.

As Parkinson’s affects balance and gait, falling is at greater risk, and the body does not cooperate to “catch” the fall.

Fear can be magnified, and inactivity becomes a dangerous outcome. As people become scared, they stop doing things, and the immobility can lead to physical deterioration. This leads to greater susceptibility to falling, and the fear feels justified. This cycle can also include withdrawal from social contacts and activities, and subsequent depression. The combination of disease, weakness and depression offers a bleak future with diminishing hope.

It has been estimated that one third of people over age 65 fall, with 10 per cent of the falls resulting in injury.

Health professionals now recognize that falls are not a normal part of aging, and that many falls do not need to happen. Environmental risks can be minimized with prudence and planning. Bathrooms can be modified with support rails, kitchens can be reorganized to alleviate over-reaching for items, non-slip floor tape can be put on tiles that are slippery, and many other techniques can be employed to ensure a safe home. Many books and articles are available for more information on this topic of home safety. The AARP Web site has an excellent article on this subject under home safety. It is titled “Does Your Home Meet Your Needs? A Checklist” (www.aarp.org).

Physical risks can be diminished as well, and the most effective way to accomplish this is through exercise. As adults lose 10

per cent of their muscular strength for every decade of life, studies have shown that after a 12 week exercise program older adults had increased their strength. Exercise also improves balance, and can improve bone density.

The emotional benefits of exercise are well lauded, as increased confidence, well-being, and a sense of control result in optimism and happiness. Another technique, learning how to fall, is an injury preventer for the likes of athletes, ice skaters, and paratroopers and these principles can be adapted to the older population.

An undergarment has been designed to lessen the impact of falls in the hip area, and these can be viewed at www.hiprotector.com. For the mobility impaired, sitting in a wheelchair and using one’s legs to propel the wheelchair affords more lower body strength than a motorized scooter. A physical therapist consultation can offer customized, individual plans and direction for these concerns.

But how can the fear be eclipsed?

Once you restrict your life, you’re finished. Everything goes.

Treating the fear involves awareness and acknowledgment, and including care providers in the discussion. The goal is reconditioning, and finding the balance between the risk of immobility and mobility.



Another aspect is to identify the reason the fall occurred, and try to correct the cause. In a study done in England, it was suggested that falls could be cut by 50 percent if post-fall assessments could be done with subsequent corrections made.

Being afraid of injury is a valid concern that shapes our lives; living in fear controls our life. Try to find a healthy regard for gravity, and live accordingly. ■

NEUROLOGICAL DISORDERS INFORMATION

The National Institute of Neurological Disorders and Stroke supports research on the brain and nervous system and publishes information for the public on many of the most common neurological disorders.

A list of the publications and copies of them may be ordered through the Institute’s Brain Resources and Information Network (BRAIN).

Mail orders to BRAIN, P.O. Box 5801, Bethesda, MD 20824, or call 1-800-352-9424. ■

NATIONAL RESCUE SUMMITS ON PARKINSON’S DISEASE AND “OFF” EPISODES

The American Parkinson Disease Association is teaming up with Mylan Bertek Pharmaceuticals to launch a series of Rescue Summits to take place across the United States over the next year. The Rescue Summits are an opportunity to advance the understanding of Parkinson’s disease and specifically “off” episodes, frustrating periods of loss of control of body movements associated with advanced Parkinson’s disease.

The Rescue Summits are composed of a morning event including a presentation by a **leading Parkinson’s expert**. The Summits welcome all Parkinson patients and care partners **FREE** of charge and **breakfast** will be served.

The Rescue Summits are tentatively scheduled to take place in the Tampa Bay area, California, New York, North Carolina and Pennsylvania. For more information about the Summits, please visit www.rescuesummit.com or call 1-877-727-6596. ■

Information on Parkinson's Disease

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

EDUCATIONAL BOOKLETS

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

EDUCATIONAL SUPPLEMENTS

Hospitalization, Helpful Hints, Living Will, Helping Your Partner, Nursing Homes, Comtan (Entacapone) The Treatment of Parkinson's Disease Question and Answers, Comtan: Extending the Benefits of Levodopa, Comtan (Entacapone) Tablets.

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

SCHWARZ PHARMA ANNOUNCES FDA APPROVAL OF PARCOPA

Orally Dissolving Tablets for Parkinson's Disease

SCHWARZ PHARMA, INC. announced that it has received approval from the U.S. Food and Drug Administration (FDA) to market Parcopa (carbidopa-levodopa orally disintegrating tablets), a unique formulation of carbidopa-levodopa that dissolves rapidly on the tongue. Parcopa is designed to provide patients suffering from Parkinson's disease improved access to this medication.

Unlike conventional carbidopa-levodopa tablets, Parcopa dissolves on the tongue using RepiTab technology to deliver without the need for water, providing patients with a convenient means to take their medication.

Parcopa is available in the same strengths and has the same dosage schedule as conventional Sinemet (carbidopa-levodopa) tablets.

For further information call 1-800-558-5114 or visit www.Parcopa.com.

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.