



The American Parkinson Disease Association

SUMMER 2007 NEWSLETTER

A Quarterly Newsletter by The American Parkinson Disease Association, Inc. ©2007

2007 Awards Raise APDA Research Funding to More than \$30 million

By PAUL MAESTRONE, DVM, Director of Scientific and Medical Affairs

The American Parkinson Disease Association (APDA) has announced its 2007-2008 fiscal year research awards,

which total more than \$3.5 million and include its ninth Center for Advanced Research, the creation of a \$100,000 contingency fund for research to assure projects in progress from being lost to institution budget cuts, and the establishment of a dedicated post-graduate geriatric psychiatry grant. It also increased its Centers for Advanced Research allocation from \$100,000 a year for five years to \$125,000 annually for the same period. The awards bring APDA's total Parkinson's disease research contribution to more than \$30 million since its inception.

The University of Chicago was chosen to join the schools of medicine at Emory University, Atlanta, Ga.; UMDNJ-Robert Wood Johnson, New Brunswick, N.J.; Boston University, Boston, Mass.; and UCLA, Los Angeles, Calif.; the medical centers at the University of Virginia, Charlottesville, and Washington University, St. Louis, Mo.; and the Universities of Pittsburgh, Pa., and of Alabama at Birmingham, as Centers for Advanced Research. Un Jung Kang, MD, is the new Advanced Center's director.

Two Dr. George C. Cotzias Memorial Fellowships, an \$80,000 grant for each of three years, were

awarded to Talene Yacoubian, MD, PhD at the University of Alabama at Birmingham, and Bradley Miller, MD, PhD at the University of Virginia. The fellowship is named for George C. Cotzias, MD, a pathfinder in pharmacological exploration of brain functions and in the treatment of Parkinson's disease with levodopa, which more than 40 years later is still the gold standard of PD medication.

Princeton University PhD, Jeffrey Stock, and Andrei Alexandrescu, PhD, of the University of Connecticut, Storrs, were named Roger C. Duvoisin, MD grant recipients, an award of \$80,000 per year for two consecutive years.

APDA's Scientific Advisory Board, which reviews and recommends all research allocations to the APDA board of directors, also chose 31 research grants and 11 post-graduate grants and three summer medical student fellowships.

Researchers at 24 institutions across the country received one-time \$50,000 research grants.

Eleven one-year, \$35,000 post-doctoral fellowships were awarded.

APDA was founded in 1961 with the dual mission to "Ease the Burden - Find the Cure" for Parkinson's disease and has grown into the country's largest grassroots organization serving persons with PD and their care-

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VINCENT N. GATTULLO
PRESIDENT

Dear Reader,

Research has been in the news quite a bit recently as several respected scientific journals reported positive results in gene therapy to alleviate clinical symptoms in persons with Parkinson's disease.

Successful scientific breakthroughs, of course -- and unfortunately -- do not mean immediate help for patients. Many more years of tests, trials, and approvals lie ahead. They do, however, offer hope and send the message that research support is paramount in our battle against disease and suffering. They also encourage scientists to persevere despite the challenges of increasing costs and funding barriers.

Such progress also gives APDA the satisfaction that our resolute efforts to support research are valid. At its annual two-day meeting this year, our Scientific Advisory Board (SAB) recommended funding for a ninth Center for Advanced Research at the University of Chicago, two Dr. George C. Cotzias Fellowships, and two Roger C. Duvoisin, MD Grants. It also favorably reviewed funding applications for 31 research and 11 post-graduate grants, recommended the creation of a contingency fund to protect research in progress from institution budget cuts, and the establishment of a dedicated geriatric psychiatry grant at the post-doctoral level. (See pages 10-11 for a complete list of awards.)

The executive committee unanimously approved all recommendations, and also voted to increase the annual APDA Centers for Advanced Research funding to \$125,000 for a five year period, bringing 2007-2008 funding to \$3.5 million and APDA's total contribution to research to more than \$30 million.

Appreciative responses from SAB members included Dr. James Bennett's observation: "I just returned from NIH (National Institutes of Health) study section where

we reviewed many excellent grants..., but can expect only 6-8 percent to get funded. In contrast, APDA is close to 40 percent funding this year. This is an amazing achievement and will do much to keep PD research alive until the NIH budget can be realigned."

Likewise, Dr. David Standaert noted, "This is a very impressive accomplishment. It will fund scientific studies that would not have been possible without APDA support, and help to train the next generation of scientists and clinicians who will work on PD. My congratulations to the organization."

It is appropriate also to recognize Dr. Paul Maestroni's 20 years of service as our director of scientific and medical affairs. After more than two decades at Hoffmann-LaRoche in Nutley, N.J., Dr. Maestroni retired as a research group leader to join APDA in 1987. His efforts in large part have resulted in our current network of 62 Information & Referral Centers across the United States, the efficient management of our educational literature and scientific research grants program and in particular, APDA's leadership in the field of international education in Parkinson's disease. He is president of the World Parkinson Disease Association, which he helped to found in 1990.

It is this combination of our will to find the cure and the quality and dedication of the people we have guiding us (including our generous donors) that has made APDA the country's largest grassroots organization serving the Parkinson's community.

Keep up the good work!

Vincent N. Gattullo
President



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Send your name and e-mail address to:

enews@apdaparkinson.org

NAGGING AND PD

By JOSEPH H. FRIEDMAN, MD
Director Neurohealth Parkinson's Disease
and Movement Disorders Center
Director APDA Information and Referral Center,
Warwick, R.I.

Parkinson's disease (PD) patients have difficulty doing two things at the same time. There is a loss of our "automatic pilot," the programs in the brain that allow us to do many complex tasks without thinking about them. As one of my patients puts it, "my good hand does what it's supposed to do, but my Parkinson hand has to be told what to do." This causes a great deal of slowness because the patient has to guide the hand and not think about the next step.

PD patients don't blink as much as other people, hence the staring expression, and they don't swallow as much as other people, hence the pooling of saliva, or the drooling. There is a problem with their "set point" for doing these small things that occur unconsciously. It's like having a thermostat that's always a little bit off. Most people blink a certain number of times per minute, but PD patients blink a bit less. Not a big deal for most, and "easily" remedied. Just ask the PD person to blink more!

Unfortunately, or fortunately, most PD patients have better things to think about than blinking or swallowing so that they can't think about blinking or swallowing all day long. It's the same with writing too small. The patient can write larger, but concentrating on writing larger interferes with thinking about what is being written.

Everyone seems to understand this, but a very similar problem occurs with posture and armswing. PD patients have a stooped posture, and they also often tilt to one side.

The spouse often tells me, "I keep telling him to stand up straight," or, "I keep reminding him to swing his arms." I then respond, "But it never works does it?" "Well, it does for about a minute." The reason it doesn't last is just like the reason PD patients can't increase their blinking or their swallowing rate.

For whatever reason, clearly related to their PD, their brain wants something different from normal. The brain says to blink less, swallow less, write small, talk softly, stoop the shoulders, shuffle, and while all of these problems can be overridden, they can only be overridden consciously, that is, while people are thinking about one particular problem. Unfortunately there are lots of other things to think about. No one can

think about his posture all day, and especially not about his blinking, his swallowing, his speech volume and smiling, all at the same time. This applies to arm swing as well.

I try to get spouses and friends to understand that telling patients to stand up straight doesn't help. It is nagging and only is helpful if the patient wants to be reminded, perhaps at a social event or for a photograph.

Telling the family to stop nagging is usually greatly appreciated by the patient. And the spouse often appreciates this as well.

Most people don't like to nag. They do it only because they feel they must, as part of their "job" as caregiver, booster, or friend. It is helpful for spouses and caregivers to hear what the limits are. "Should I nag more? After all he's not standing up straight and if I pester him enough, maybe he'll straighten out." It helps to be told not to do it. The spouse can tell the children, "No, I'm not going to bug him anymore. The doctor said he can't help it, and this is nagging."

A more difficult problem is tilting. Some PD patients tilt to one side like the Leaning Tower of Pisa. Some patients will tilt so much that their head is on the armrest of the chair and their arm is on the floor. The most amazing thing is that patients are rarely uncomfortable from this. It looks like torture, and I certainly wouldn't want to sit like that, but the patients who do sit with their head almost parallel to the ground are not bothered. It doesn't help to say, "Sit

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BY ENRICO FAZZINI, DO, PhD
 Associate Professor Neurology
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 N.Y. Institute of Technology, Old Westbury



Q: I'd Like to know if it is possible to take Stalevo (110mg x 3 daily) together with Requip (3mg x 3 daily) if I have low pressure (110/60)?

A: It is very common to have blood pressure alterations in patients with Parkinson's disease. The disease itself can lead to low blood pressure which occurs upon standing and high blood pressure during the night. The low pressure can be alleviated by taking medications such as fludrocortisone (Florinef®) and midodrine (Proamatine®) and by reducing medications for Parkinson's disease, which can lower blood pressure (especially dopamine agonists like Requip® and Mirapex®). The high blood pressure during the night is due to lying down and is worsened by the fact that patients do not take Parkinson's disease medications during the night. This is sensed by the body (kidneys) as being too much fluid and contributes to the nighttime urinary frequency and diuresis. The nighttime diuresis can be lessened by elevating the head of the bed and taking medications to reduce urinary bladder irritability (Detrol®, Vesicare®, Enablex®, Ditropan®).

In your case, the blood pressure must be taken lying, sitting and standing and, if there is a drop which is leading to dizziness, sweating or fainting, it should be treated either by taking Florinef and/or Proamatine and by reducing the Requip. If the blood pressure is 100/70 while standing and is not associated with symptoms of dizziness, sweating or fainting it does not need to be treated. One last point - many times a patient may complain of fatigue or balance

impairment, and this can be due to low blood pressure upon standing.

Q: I'm a 63 year old man. It has been for two years that I'm suffering Parkinson disease. My body has been slow and also my left hand trembles when I want to move it. I have some questions and I would be thankful if you give me the answers.

- 1) What can cause Parkinson and can it be prevented or treated?
- 2) Does the loss of brain hormones or other losses of hormones cause the disease, and what can be the medicines?

By the way, I'm using Levodopa and Biperiden 2. I think that Biperiden 2 makes me suffer more. What can I do?

A: 1) We are not certain as to what causes Parkinson's disease, but it seems to be due to a combination of genetic and environmental factors. Parkinson's disease can be treated but not cured. There are no medications that have been proven to prevent progression.

2) There has not been proven to be a loss of brain hormones, which is associated with causing Parkinson's disease.

3) Biperiden is in the class of medications called anticholinergics and even though it can help rigidity and tremor, it may cause blurry vision, constipation, urinary retention, dry mouth and memory loss. Discuss with your doctor whether it should be reduced or discontinued.

Q: My husband is having a hard

time. He complains of not having any energy, sleep disorders (nightmares and waking up during the night; he sleeps most of the time during the day). He has no control of some of his muscles, but not the shakes. Also, sometimes he is unable to walk. Could this be because of chemical unbalance? Besides his PD pills, he takes pills for his thyroid and a pill at night called Ativan, also Flomax. Thank you.

A: There are many sleep disorders associated with Parkinson's disease. Patients may move excessively while asleep, dream vividly, and awaken numerous times during the night because of muscle cramps, tremors, and/or increased urination frequency. Disruptions of the sleep/waking cycle are common with sleepiness during the day when medications kick in or wear off. In some cases patients cannot fall asleep because their medications make them overactive and obsessive.

A new schedule must be implemented. Patients must wake up and go to sleep, eat their meals and take their medications at the same time everyday. Sleep should be induced with short-acting preparations in order to establish the new sleep times. Medications like Ativan are not good for chronic use and may themselves cause confusion. Parkinson's disease medications should not be given too close to bedtime. If excessive dreams or hallucinations occur, the entire regimen of medications needs to be reassessed and more reliance placed on immediate - release L-Dopa preparations and the use of antipsychotics like Seroquel given at bedtime. ■

F.Y.I. is a guide to the efforts and successes and recognition 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.

Ben White:

Mayor/Coordinator

It's all in Ben White's genes!

The APDA Bryan, Texas I&R coordinator can trace his healthcare inclinations to his father, brother and an uncle—all of whom were physicians. Not wanting to pursue that course, he became a high school football coach for three years, but the genes were there and after working for a San Antonio pharmaceutical firm, his career path was determined. After 20 years as director of the Bexar County Medical Society, he headed the 7,000-member Texas Dental Association for the next five years, and thought he ended his working career with two years as the executive director of the National Association of Medical Staff Services in Austin, Texas.

During their 26-year residence in San Antonio, the Whites lived in a suburban community named Garden Ridge. Ben was active in the civic association and was a pioneer in moving the community into city status and becoming its mayor pro-tem and second mayor for 11 years.

"I thought our move to College Station was to retirement," he said, but with his healthcare and government service reputation and youthful vitality, those in College Station had other ideas. And, of course, there were those genes.

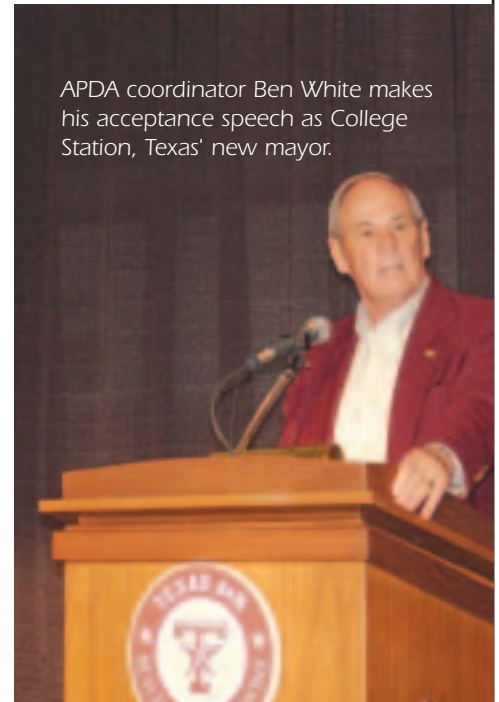
"Bill Erwin, who started the APDA-affiliated support group in College Park and led its growth into a chapter, approached me about becoming the APDA coordinator at St. Joseph Regional Rehabilitation Center in 2002. Ben's healthcare genes kicked in. Meanwhile, his government genes had him serving on the planning and zoning com-

mission, the police and fire academies, and then the College Station City Council.

It was not long before he was asked to run for mayor.

College Station is a college town (Texas A&M) of almost 85,000 people, only 10 percent of which is over age 50. "We are a young, growing city," the new mayor says, "with R&D attracted here because of the university. We need to be proactive and not reactive in that growth."

Ben plans to concentrate on building infrastructure to accommodate that growth during the three years of his term—which could be become six years, if reelected, and with the support of his wife of 51 years, Shirley, whom he calls the perfect first lady, continue following his genetic path of serving people in sickness and in health. ■



APDA coordinator Ben White makes his acceptance speech as College Station, Texas' new mayor.

Tax Benefits for Gifts from IRAs

The new Pension Protection Act allows contributions from Individual Retirement Accounts (IRA) to charity without paying income tax on the distribution. Anyone 70 1/2 years or older is eligible to donate up to \$100,000, meeting all or part of the required minimum distribution, by Dec. 31, 2007, when the law expires.

For those planning charitable gifts and do not want the extra taxable income from their required distribution, the new law provides an opportunity for tax savings combined with charitable giving.

There is no addition tax deduction for a gift of IRA funds through this law. Because you avoid income tax on any

funds transferred to charity, you are in effect already receiving a charitable deduction for all those funds since all IRA funds are pre-tax dollars.

The institution holding the IRA account can provide detailed information and most have a special form to fill out. ■

APDA SADLY NOTES THE DEATHS OF TWO VALUED AND BELOVED PARTNERS.

Belle Blumberg Englander, the founder and president of one of APDA's oldest chapters, the J. Louis Bloomberg Chapter in Philadelphia, passed away on May 7. She was 94 and continued her passionate work in memory of her father who died in 1964 from complications of Parkinson's disease. When FYI interviewed her in 2004, she was the only member of the chapter left but continued to collect memorials in the Philadelphia area and send thousands of dollars to APDA for research each year. When asked how she could carry on alone, she said, "How can I give up? How can you give up on something that is so much in your heart? We must all keep working to find a cure." Her brother-in-law Leon Aaron has become president and with her sister, Tossi, will carry on her quest.

Ernesto Garza, MD, medical director of APDA's New Mexico Information & Referral Center in Albuquerque, died on June 27.

Dr. Garza, a rehabilitation specialist known for his compassionate patient care, was diagnosed with Parkinson's disease seven years ago but continued to work five hours a day until his death. He was 50 years old. Coordinator Zella Galya, who worked with Dr. Garza during the past year, remembers him as, "a model for many of his patients. He was an inspirational man...always compassionate toward his patients. He always had time for anyone who needed to speak with him. It was an honor to work with him and to know him." ■

Flower Power for Parkinson's

40% donation to PD research

Help APDA in the fight against Parkinson's disease. Make a visible statement and a 40% donation to Parkinson's research at the same time.

We have chosen the breathtaking red tulips with a small white edge, the traditional symbol of hope for Parkinson's disease. These mid-spring bloomers produce egg-shaped flowers on 20-to-24-inch stems and are appropriate for planting in containers for balconies and patios as well. Packages contain 25 top-size bulbs, and make wonderful gifts.

The best part is that APDA will receive 40% of the price (including shipping costs) of every package of tulips purchased. So, when planting your beautiful tulip bulbs, you are also planting hope for the cure.

Share this offer with friends and family and help Parkinson's research even more. The price per bag, \$29.95, includes all shipping and handling charges. Orders must be received by September 15, 2007.

Shipping & handling:

1. Order online at: www.tulipworld.com/APDA
2. Call toll free 1-866-688-9547

APDA logo: TO LIVE THE BANNER TO FIGHT THE DISEASE



IS FOR AWARENESS IN THE APDA ALPHABET

APDA's successful efforts for the 2007 Parkinson's Awareness Month are still being reported. To the last report of seven governors who proclaimed April as Parkinson's Disease Awareness Month, now can be added Donald Carciere (R.I.), Rick Perry (Texas), James Doyle, Jr. (Wis.), Jim Douglas (Vt.), Tim Pawlenty (Minn.) and Governor and presidential hopeful Bill Richardson of New Mexico.

In Texas, Dallas, Mayor Laura Miller, and in San Antonio, Mayor Phil Hardberger also issued proclamations.

The New Mexico Chapter, led by its president, Bobby Dunagan, was responsible for 15 proclamations including the state governor, major city mayors and the presi-

dent of the New Mexico Navajo Nation, Albert Davis.

In Front Royal, Va., Warren County Parkinson's Support Group leader Lee Mangene stopped by Town Hall to distribute awareness flyers and decided to welcome the new town manager back to Front Royal. The two knew each other from years past. After talking with Lee, he insisted on a banner and despite Lee's financial objections, offered to pay for it out of his own pocket. Enter APDA friend No.2 - Shea Parker, owner of Hanna Signs. Shea not only produced a larger, four-color banner, but also reduced the final price by \$400. Thus, the residents and visitors to Front Royal in April could not but know it was Parkinson's Disease Awareness Month. ■

SUPPORT GROUPS ARE THE "ROOTS" IN APDA'S GRASSROOTS NETWORK

APDA is proud to be the country's largest grassroots organization serving the Parkinson's community, and, support groups are the "roots" in "grassroots." Lee Mangene is the founder and facilitator of the Warren County Parkinson's Support Group in Front Royal, Va., and shares her experiences in starting a successful support group in FYI's first profile of support groups and their leaders.

“I just don't have the time,” is often the reason people don't even think of starting a support group. And it is understandable when he/she has Parkinson's disease or is a caregiver, which many support group founders are. But then there are people like Lee Mangene - caregiver, mother of eight, grandmother of 23, and great-grandmother of three - so far, whose personal words to live by are, “What you do for yourself, dies with you, what you do for others lives forever.”

When Lee's husband, Charlie, was diagnosed in 2000, two years after retiring from operating his Exxon service stations, Lee wanted to know everything about the disease and sought a support group. The group listed at Winchester Hospital turned out to have disbanded, and a second one listed in the telephone book had met the same fate. She turned to Warren Memorial Hospital in her hometown, and Kay Largent, now community outreach director, then education director, offered to provide the meeting place, if Lee wanted to start one.

“So, I made up flyers and distributed them all over Front Royal. The first meeting no one appeared. The second meeting, I got one phone call, but I refused to give up. The third meeting a man appeared with his wife, who was wheelchair-bound. They lived in the Southerlands, an assisted living facility in Front Royal, and he indicated that he would not be able to continue attending meetings at the

hospital, but would I consider having the meetings at the Southerlands?”

Lee would consider it; the Southerlands would be happy to host the meetings, and the rest, as they say, is history. The Warren County Parkinson's Support Group meets every Wednesday at 1 p.m. with an attendance of between 25 and 35 members from as far as Berkeley Springs, W. Va., 60 miles away. In addition to meetings, the group sponsors an annual symposium at the Bowling Green Country Club in Front Royal, Va., attended by 75 to 100 people.

“We have a formal membership, but no dues,” Lee explains. “The Southerlands supplies beverages and the hospital continues to provide a tray of cookies.”

Lee credits former APDA Information & Referral Center coordinator at the University of Virginia, Miriam Hirsh, RN, for her support during the startup days, and still works closely with Miriam's successor, Susan Dietrich, in identifying speakers and assisting in meetings and events.

Lee admits that starting the group took determination, organization, and footwork. She delegates, “but I'm accused of not delegating enough.”

She also says that the social bonds formed by members are more than worth the effort.

“We have a telephone exchange list and members have formed friendships among themselves. Getting a hug from someone you've helped is worth all the effort,” she says. ■



Charlie and Lee Mangene celebrate Christmas during a Warren County Parkinson's Support Group meeting.

MEMORIAL GIFTS RECOGNIZED

In future issues of the Quarterly Newsletter, APDA will publish the names of those who have been submitted in honor of or in memory of by their family and friends with a \$50 contribution or more to APDA's efforts to “Ease the Burden - Find the Cure.” Donations of any amount will be acknowledged by mail and the honoree made aware of the contribution in his/her name. ■

HOW TO START A SUPPORT GROUP

APDA's new flyer, “How To Start a Support Group,” is available by contacting **Emily Ciorciari** at: **800-223-2732, ext. 115** or **eciorciari@apdaparkinson.org**.

Lee Mangene also invites anyone who would like to talk about starting a PD group to contact her at **540-635-8122**.



CAREGIVING RECOGNIZING SIGNS OF BURNOUT

BY JO BIDWELL, Coordinator APDA Information and Referral Center, Lubbock, Texas

Burnout is not something to be ashamed of or to deny. Most parents have suffered burnout, either by endlessly walking the floors when a newborn has colic or nightly pacing the floors when a teenager starts dating or driving. Burnout is even more common when you are caring for a loved one who is sick. In most cases caregiver burnout occurs because the caregivers are trying to do too much or because they are trying to do everything by themselves.

Common symptoms of caregiver burnout include, but are not limited to the following:

- Extreme fatigue or exhaustion
- Feelings of hopelessness or helplessness
- Changes in eating or sleeping habits
- Loss of interest in family, friends or activities
- Irritability or anger
- Anxiety or depression
- Guilt

Caregivers are often so busy taking care of others that they neglect their own needs. The physical and emotional demands that are placed on caregivers affect their mind, body and spirit.

The Cleveland Clinic has identified several factors that may lead to caregiver burnout. These are:

1. Role confusion: Many people are confused when thrust into the role of caregiver. It can be difficult for a person to separate her/his role as caregiver from her/his role as spouse, lover, child, friend.

2. Unrealistic expectations: Many caregivers expect their involvement to have a positive effect on the health and happiness of the patient. This may be

unrealistic for patients suffering from a progressive disease, such as Parkinson's or Alzheimer's.

3. Lack of control: Many caregivers become frustrated by lack of money, resources and skills to effectively plan, manage and organize their loved one's care.

4. Unreasonable demands: Some caregivers place unreasonable burdens upon themselves in part because they see providing care as their exclusive responsibility. Some family members such as siblings, adult children or the patient himself/herself may place unreasonable demands on the caregiver. These individuals also may disregard their own responsibilities and place burdens on the person identified as primary caregiver.

5. Other factors: Many caregivers cannot recognize when they are suffering burnout and eventually get to the point where they cannot function effectively.

If you are a caregiver here are some simple, yet effective suggestions to help you from falling into the trap of caregiver burnout.

1. Find a confidant to talk to. It is best not to choose another family member, rather choose a co-worker, friend, neighbor or friend whom you can trust to share your inner most feelings and frustrations with. Use that person often.

2. Realize that you are not a superhuman. There are truly limitations to what you are capable of doing. Do not expect to do more and do not let others put pressure on you to do more than you are capable of doing.

3. Take care of yourself. This should not be seen as a luxury, rather

as a necessity. I often tell people that if the caregivers do not take care of themselves then they may soon need a caregiver of their own. On more than one occasion since I began this job ten years ago, the appointed caregiver has ended up having a stroke or heart attack and could not take care of his/her patient. Taking care of yourself means getting a balanced diet, making time for daily exercise and getting enough rest.

4. Take advantage of friends, coworkers, family members, etc. who offer to help. As a matter of fact, don't just take advantage, but be prepared - when someone offers, have specific jobs that they could do to be of service to you. This could be everything from cleaning out the gutters, to sitting with your patient so you could have your hair done, to preparing a casserole so when you are too tired to cook you would have something in the freezer. Remember, if they did not want to help, they probably would not have offered. If they offered and really did not want to help then they will probably never offer again, but that is OK too.

5. Look for respite care services. This can be for a few hours or even a few days. We all need to take a vacation from our every day activities.

6. Last, don't be afraid to consult a professional. It is normal to reach a point where you are overburdened. A large number of caregivers sometimes rely on medication, at least for a short period of time to help "get them over the hump." Please understand, I am in no way an advocate of popping pills, but sometimes when we have reached that point, they become a necessity. ■

THE FIVE Rs OF EXERCISE

By DAVID KING, PT.



Most folks don't like to exercise: it takes time and effort and often it is not fun. But for the Parkinson's sufferer it is absolutely essential to keep moving as much as possible and exercise can help in that quest.

The ideas I apply to exercise are to try to answer as many of the symptoms of Parkinson's as

I can in any given moment and to make the exercise relevant to the individuals and their specific sets of symptoms. And as much as possible I try to make the exercises fun.

Some of the common symptoms I try to answer with exercise include difficulty initiating movement, difficulty changing direction, stiffness of the joints and poor balance. I have developed the 5Rs of exercise design as a way to try to address as many symptoms as possible.

Rotation. Walking requires us to rotate all up and down our body in ways large and small. This is most evident in the disassociation of limb movements - one limb moving forward while the other is moving back and in the coordination of opposite arms and legs. Studies on treadmills have shown that rotation increases with speed as a means of maintaining balance. A person unable to rotate his trunk will feel more out of balance and will only willingly walk at slow speeds. Some exercises that incorporate rotation include dancing, swinging a bat or tennis racquet, T'ai-chi and water aerobics. Lying on your back and dropping your knees side to side is a gentle exercise to try at the start of your day.

Rhythm. The nervous system includes an "internal clock mechanism," it is how we are aware of the passage of time and how we are able to compute time, speed and distance with regard to moving around objects or dealing with others in a moving crowd. This mechanism is affected by Parkinson's disease. Exercises that include cadence

help the nervous system cope with the damage to its internal clock or exercising to music can assist the cadence of exercise. Exercises might include dancing, tennis, catching and throwing a ball or just walking.

Range of motion. Stretching muscles helps reduce rigidity and pain. Moving joints through their range of motion helps prevent losses of the end of their range and prevents stiffness. It is best to time stretching exercises to the time when medications provide the most relief so as to avoid injury to overly tight muscles. Exercises could include stretching, throwing a ball, T'ai-chi, yoga and water aerobics.

Reaction. Research has found that it is easier to move if it is done in reaction to an external stimulus. For example someone having difficulty raising his hand might do more quickly if done to catch a ball thrown to him. This adds the benefit of rehearsing the interpretation of sensory input. Also I have often set up obstacle courses made of simple blocks and steps either to step on or step over. Obstacle courses need not be in a straight line and can challenge the person to vary step length as well as change directions.

Rehearsed movements. Movements that are familiar are easier to repeat and adjust to changes. If you used to dance, try it now. If you used to play tennis, go bounce some balls off a back board. If you used to golf go to the driving range or the putting green. Your body and nervous system are changing but your nervous system will more readily adapt to these changes with a familiar movement than with an exercise that is completely new.

Not every exercise will address all five Rs, but the more the better. And sometimes one R can be used to make addressing another R easier. Reacting to an incoming tennis ball to perform the rehearsed movement of swinging the racquet and thereby increasing rotation and shoulder range of motion includes four R's and is fun!

This article appeared in the New Brunswick, N.J. APDA I&R Center newsletter of Spring 2007. ■

2007 AWARDS *(cont. from pg. 1)*

givers. In addition to its \$30 million research funding, APDA has contributed more than \$28 million to patient and caregiver support through its network of 62 Information & Referral Centers and 800 support groups across the country.

"We take our mission very seriously," said APDA president Vincent Gattullo, "and are extremely proud that we have been a funding partner in every scientific breakthrough in Parkinson's disease since we were founded 46 years ago." ■

APDA RESEARCH FUNDING

Centers for Advanced Research

Emory University School of Medicine, <i>Atlanta, Ga</i>	Robert Wood Johnson Medical School <i>New Brunswick, NJ</i>	Boston University School of Medicine <i>Boston, MA</i>
UCLA School of Medicine <i>Los Angeles, CA</i>	Washington University Medical Center <i>St. Louis, MO</i>	University of Virginia Medical Center <i>Charlottesville, VA</i>
University of Pittsburgh <i>Pittsburgh, PA</i>	University of Alabama <i>Birmingham, AL</i>	The University of Chicago <i>Chicago, IL</i>

Cotzias Fellowships

Bradley Miller, MD, Ph.D.	University of Virginia, <i>Charlottesville, VA</i>	Distribution and Metabolic Consequences of Mitochondrial DNA Deletions in Substantia Nigra and Cultured Cells
Joseph Savitt, MD, Ph.D.	John Hopkins Hospital, <i>Baltimore, MD</i>	Conditional GDNF Receptor Knockout Mice: Exploring the Role of GDNF in Dopaminergic Cell Development and Survival
Talene Yacoubian, MD, Ph.D.	The University of Alabama, <i>Birmingham, AL</i>	Role of 14-3-3 Proteins in Alpha Synuclein Induced Neurotoxicity

Roger Duvoisin, MD Grants

Andrei Alexandrescu, Ph.D.	University of Connecticut <i>Storrs, CT</i>	Stability and Solvent Accessibility of Alpha-Synuclein Fibrils by NMR Hydrogen Exchange
James L. Roberts, MD, Ph.D.	University of Texas Health Science Center <i>San Antonio, TX</i>	Molecular and Cellular Mechanisms of Estrogen Mediated Neuroprotection of Mesencephalic Dopaminergic Neurons
Jeffry Stock, Ph.D.	Princeton University <i>Princeton, NJ</i>	Protein Phosphatase 2A Methylation as a Therapeutic Target for Parkinson's Disease

PostDoctoral Fellowships

Michelle Burack, MD, Ph.D.	University of Rochester <i>Rochester, NY</i>	The Impact of Dopa-Induced Dyskinesia on Voluntary Motor Control in Patients with Idiopathic Parkinson Disease
Joanne Clark, Ph.D.	Beth Israel Deaconess Medical Center <i>Boston, MA</i>	Activation of PGC1 α by P38MAPK; Potential Interference by A-synuclein
Clement Gautier, Ph.D.	Brigham and Women Hospital <i>Boston, MA</i>	Investigation of Mitochondrial Functions in PINK 1 Knock Out Mice
Melissa Geddie, Ph.D.	Whitehead Institute for Biomedical Research, <i>Cambridge, MA</i>	Metal Ion Transport in Parkinson's Disease
Keiichi Inoue, Ph.D.	Columbia University <i>New York, NY</i>	Novel Animal Models of PD
Shilpa Iyer, Ph.D.	University of Virginia <i>Charlottesville, VA</i>	In Vitro Characterization of Mechanisms of Mitochondrial DNA Homoplasmy
Nikolaus McFarland, MD, Ph.D.	Massachusetts General Hospital <i>Boston, MA</i>	Alpha-Synuclein Phosphorylation and Toxicity in a Rat Model of Parkinson's
Julie Tetzlaff, Ph.D.	Massachusetts General Hospital <i>Boston, MA</i>	Therapeutic Reduction in Oligomeric Alpha-Synuclein Species
Shaji Theodore, Ph.D.	The University of Alabama <i>Birmingham, AL</i>	A Novel Mode of Microglial Activation in a Mouse Model of Parkinson's Disease
Harrison Walker, MD	The University of Alabama <i>Birmingham, AL</i>	Clinical and Electrophysiological Investigation of Bilateral Effects of Unilateral Subthalamic Nucleus Deep Brain Stimulation
Allison Wright Willis, MD	Washington University <i>St. Louis, MO</i>	Environment Heavy Metal Exposure and the Risk of PD: A Community Health Study Using Geographical Information Systems

Research Grants

Asa Abeliovich, MD, Ph.D.	Columbia University <i>New York, NY</i>	Novel Therapeutics for PD
Sarah Berman, MD, Ph.D.	University of Pittsburgh <i>Pittsburgh, PA</i>	Exploration of Mitochondrial Dynamics in Models of Parkinson's Disease
Guy Caldwell, Ph.D.	The University of Alabama <i>Tuscaloosa, AL</i>	Identification and Functional Validation of Neuroprotective Genes Associated with Parkinson's Disease
Sreeranga Chandra, Ph.D.	Yale University <i>New Haven, CT</i>	Delineating the Physiological Functions of Synucleins
Sylvain Dore, Ph.D.	Johns Hopkins University School of Med. <i>Baltimore, MD</i>	PGE2 EP1 Receptor Role in Parkinsonism

FOR FISCAL YEAR 2007-2008

Research Grants

Ray Dorsey, MD	University of Rochester <i>Rochester, NY</i>	A Guide to Improving the Impact of Parkinson Disease Research
Andrea Giuffrida, Ph.D.	University of Texas Health Science Center <i>San Antonio, TX</i>	Neuroprotective Role of Cannabinoids in Parkinson's Disease
Matthew Goldberg, Ph.D.	UT Southwestern Medical Center <i>Dallas, TX</i>	Parkin, DJ-1 and Antioxidant-deficient Mouse Models of PD
Ming Guo, MD, Ph.D.	Brain Research Institute at UCLA <i>Los Angeles, CA</i>	Characterization of the Function of a PINK 1 Binding Protein
Syed Iman, Ph.D.	University of Texas Health Science Center <i>San Antonio, TX</i>	Evaluation of Stress-induced Tyrosine Kinase, c-Abl, as a Novel Therapeutic Target for Parkinson's Disease
Steven Johnson, MD, Ph.D.	Portland VA Research Foundation <i>Portland, OR</i>	Redox Regulation of NMDA Currents in Midbrain Dopamine Neurons
Andreas Kottmann, Ph.D.	Columbia University <i>New York, NY</i>	On the Function of the Secreted Cell-Signaling Glycoprotein Sonic Hedgehog (Shh) Expressed by Mesencephalic Dopaminergic Neurons in the Postnatal Brain
Lawrence Kromer, Ph.D.	Georgetown University <i>Washington, DC</i>	Role of Ephrins and Eph Receptors in Regulating Striatal Reinnervation by Dopaminergic Grafts
Matthew LaVoie, Ph.D.	Brigham and Women's Hospital <i>Boston, MA</i>	Dissecting the anti-Apoptotic Function of Parkin and the Impact of PD-Linked Parkin Mutations
Zhicheng Lin, Ph.D.	The McLean Hospital Corporation <i>Belmont, MA</i>	Genetic Variation in Human Alpha-Synuclein Expression
Changwei Liu, Ph.D.	University of Colorado at Denver <i>Aurora, CO</i>	Studying the Role of the CHIP/Hsp70 E3 Ligase in Mediating the Ubiquitination of Serine 129 Phosphorylated Alpha-Synuclein
Nigel Maidment, Ph.D.	UCLA <i>Los Angeles, CA</i>	Is VMAT Over-Expression Neuroprotective in Mammalian Alpha-Synuclein Models of PD
Anthony Nicholas, MD, Ph.D.	The University of Alabama <i>Birmingham, AL</i>	Post-Translational Modifications of Histones in Levodopa-Induced Dyskinesia
Janis O'Donnell, Ph.D.	University of Alabama <i>Tuscaloosa, AL</i>	In Vivo Analysis of the Role of 14-3-3 Zeta and Over-expression in Neurodegeneration in a Drosophila PD Model
Owen Ross, Ph.D.	Mayo Clinic Jacksonville <i>Jacksonville, FL</i>	Dysregulation of A-Synuclein Gene Expression in Parkinson's Disease
Jay Schneider, Ph.D.	Thomas Jefferson University <i>Philadelphia, PA</i>	Functional Significance of ALDH1 in Ventral Mesencephalic Dopamine Neurons
Lidia Serova, Ph.D.	New York Medical College <i>Valhalla, NY</i>	Mechanism of Interaction Between Nicotine and Estradiol as Related to Tetrahydrobiopterin in Animal Model of Parkinson's Disease
Paul Shaw, Ph.D.	Washington University <i>St. Louis, MO</i>	Evaluating Protective Effects of Curcumin in Synuclein Pathology
Wanli Smith, MD, Ph.D.	Johns Hopkins University School of Med. <i>Baltimore, MD</i>	Cytoplasmic LRRK2 Inclusion and Ubiquitination
Stephanie White, Ph.D.	University of California <i>Los Angeles, CA</i>	Birdsong as a Model System for Parkinson's Disease
Stephan Witt, Ph.D.	Louisiana State University Health Sci. Ctr. <i>Shreveport, LA</i>	Determining Why Phosphorylation of Alpha-Synuclein at Serine 129 Causes Toxicity
Baoji Xu, Ph.D.	Georgetown University <i>Washington, DC</i>	Chronic Deprivation of TrkB Signaling Leads to Progressive and Selective Nigrostriatal Dopaminergic Degeneration
Jin Xu, Ph.D.	Caritas St. Elizabeth's Medical Ctr. <i>Boston, MA</i>	Functional Interplay Between DJ-1 and PGC-1 α
Cyrus Zabetian, MD, MS	Seattle Institute for Biomedical & Clinical Research, <i>Seattle, WA</i>	Fine-mapping of a Chromosome 17q21 Region Associated with Parkinson's Disease
Fu-Ming Zhou, Ph.D.	University of Tennessee <i>Memphis, TN</i>	An Ultra-Short Dopamine Pathway: Implications for Parkinson's Disease
Wenbo Zhou, Ph.D.	University of Colorado Health Sci. Ctr. <i>Denver, CO</i>	Testing Drugs that Upregulate DJ-1 in Mouse Models of 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, or contacting any of the 62 APDA Information and Referral Centers.

EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**
Brochure (English, Chinese, Spanish, Portuguese, Russian)
2. **Parkinson's Disease Handbook**
Symptoms, causes, treatment; 40-page booklet (English, German, Italian)
3. **Be Active** - A suggested exercise program for people with Parkinson's disease; 25-page booklet (English)
4. **Be Independent**- Equipment and suggestions for daily living activities; 22-page booklet (English)
5. **Speaking Effectively** - Speech and swallowing problems in Parkinson's disease; 34-page booklet (English)
6. **Good Nutrition** - 20-page booklet (English)
7. **Young Parkinson's Handbook** - 78-page booklet (English)
8. **Aquatic Exercise for Parkinson's Disease** - 20-page booklet (English)
9. **My Mommy Has PD... But It's Okay!** - 20-page booklet for young children.

The Next Step After Your Diagnosis: Finding Information and Support-Booklet can be obtained by calling 800-358-9295 and requesting booklet AHRQ Publication No. 05-0049

EDUCATIONAL SUPPLEMENTS

Caring for the Caregiver: Body, Mind and Spirit; The Family Unit; The Fine Art of "Recreation & Socialization" with PD; Medical Management of PD; Neuro-ophthalmology and Vision; Mirapex® in the Treatment of PD; Fatigue in PD; Healthy Aging.

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, 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 and research application guidelines.

WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

www.wpda.org. A weekly updated source of world news.

NAGGING AND PD (cont. from pg.3)

up straight." The brains in these patients are confused about what straight and up and down are. The best thing to do in these cases is to stuff the chair with pillows and try to keep them as erect as possible.

I don't know what to do when PD patients fall a lot. I have been impressed by how many PD patients fall in particular situations that they know are problematic and should be able to anticipate. Most patients fall when they try to turn and their feet stick to the ground. So, why don't they simply learn to cope with this by stopping, turning with a few small steps, or by leaning against a wall? I've asked some patients this and I always get a shrug. I also hear from the caregiver that the patient is constantly being told, "Be careful. Turn slowly." "Don't take your hands off the walker." Yet it happens daily or more. I used to say the same thing. "Stop and think before you turn."

One day I had a sudden insight. There are not many stronger reasons for learning than very bad experiences. If you do something that results in a very bad outcome, you avoid doing the same thing again. If you stick a fork in the socket, you learn with a single experience to never do that again. Why is it that a PD patient who falls can do the same thing over and over again? I don't know, but I realized one day that if a fall won't teach patients the danger, then my telling them or their spouse's nagging isn't very likely to help either.

What's the solution? I don't know. It's hard to keep from trying to help. On the other hand, we must learn to avoid nagging. Nagging is demoralizing for the nagger and the naggee. The nagger feels ignored and the one being nagged feels misunderstood or morally weak, as if not trying hard enough.

Nagging about exercising is good though. You can always nag each other about exercising more. It's good for everybody. ■

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.