



The American Parkinson Disease Association

SUMMER 2008 NEWSLETTER

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Cells and Parkinson's Disease

By Thomas G. Hammond, MD, Director, APDA I&R Center, Deerfield Beach, FL

Cell Loss

In Parkinson's disease (PD), the principal symptoms of tremor, slowing of movement, muscle stiffness/rigidity and eventual impairment of balance are correlated with loss of cells in the sub-

stantia nigra (SN) in the brainstem. When PD patients show the first signs of slowness or tremor, they have already lost 70% of the pigmented neurons that make dopamine (DA) in the SN. This leads to the neuro chemical DA deficiency which we treat with medications such as L-Dopa. The cause for cell death in the SN in patients under the age of 50 is often genetic. In this younger age group, which accounts for only about 1% of PD patients, gene coding for abnormal proteins such as synuclein are implicated in causing the SN cells to die. In those patients developing PD after the age of 50, genetic factors are less significant and environmental factors seem more important. Head trauma, such as occurring in contact sports like boxing, is implicated as a risk factor. PD occurs 1.35 times more often in people who have been knocked out once compared with those who have never been knocked unconscious. The PD occurrence jumps to 2.53 times more often in people who have had more frequent episodes of being knocked out. This factor clearly played a role in the development of Parkinson's disease in Muhammad Ali.

Pesticides have been implicated in causing PD since people with low levels of pesticide exposure have 1.13 times the risk as compared to people without pesticide exposure. High levels of pesticide exposure lead to 1.41 times the likelihood of developing the disease.

Recent work at the University of Kentucky in Lexington, revealed trichloroethylene (TCE) exposure as a

risk factor for developing Parkinsonism and possibly a cause for PD. TCE is an industrial chemical used in manufacturing. Unfortunately, it turns up in drinking water and soil due to runoff from manufacturing sites where it is used. It is found in 60% of the superfund priority sites identified by the Environmental Protection Agency. The University of Kentucky researchers examined workers who had been exposed to TCE and found symptoms and signs of PD such as slowing of movements (akinesia), stooped posture and balance problems. The symptoms seemed to be associated with the level and duration of TCE exposure. Furthermore, they performed experiments on rats with TCE exposure and were able to show that it inhibits the function of the mitochondria (energy organelles) in the cells.

Mitochondrial dysfunction has been implicated as a problem in PD and in fact Coenzyme Q10 (Co-Q10) is felt to have possible benefit in PD due to its beneficial effect on mitochondrial function. MPTP is a street drug used by addicts to get "high" and is a known cause for Parkinsonism/PD in humans. MPTP, like TCE, seems to be toxic to the mitochondria especially in the SN cells in the brainstem. In animal models, both agents cause neurodegeneration and a PD type picture. Further epidemiologic studies on TCE and PD are ongoing.

Cell Protection

A recent study supports the concept that neuro-inflammation in the SN is playing a role in the death of cells in

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Dear Reader:

Research is the major segment of APDA's expenses. Our latest annual report shows that 31 percent of our spending is for research with our Information & Referral Centers 23 percent, and education 18 percent. As you will read in this issue, our contribution to scientific research for the 2008-2009 year is \$3.7 million to 38 academic and medical centers in the United States pursuing the most promising studies.

With federal funding for the National Institutes of Health (NIH) at an inadequate 0.46 percent increase for this fiscal year, it is particularly significant that APDA research funding supports American research. Biomedical inflation is well above the NIH increase, and without other means of support, necessary clinical and translational research for Parkinson's is suffering. A criterion for all APDA funding is that the research must be carried out in an institution in the United States.

We are also proud of our funding methodology, which supports advanced research at the most prestigious institutions as well as providing opportunities for medical students to perform supervised laboratory or clinical research. The reason for the former is self-evident; the latter is to stimulate a student's interest in pursuing a career in research in the Parkinson's disease area.

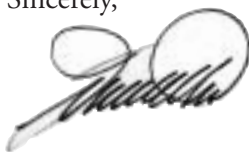
Our most prestigious award, the George C. Cotizas, MD Fellowship, is also given to a young neurologist to encourage him/her in establishing a career in research, teaching and clinical services relevant to Parkinson's disease. Six recipients have gone on to become chairmen of prominent academic departments of neurology, and four presently serve as members of APDA Scientific Advisory Committee, including its chairman, G. Frederic Wooten, MD, of the University of Virginia.

Last, but certainly not least, is our reputation for providing the seed-money for young researchers to gather the necessary data for greater funding from the NIH and other larger endowed organizations and institutions. Without the initial funds to begin a study, the most promising research can go nowhere and the possible cause and cure never discovered or at least be delayed for many years.

APDA's contribution to research is paramount in its effectiveness at all levels. Equally unparalleled is its service of education and support to persons with PD and their caregivers, making it the largest grassroots organization serving the PD community in the United States.

If I sound proud, I am as should every person who has ever contributed to this research tradition.

Sincerely,



Vincent N. Gattullo
President

Requip®XL™ Approval by FDA

Requip®XL™ (ropinirole extended-release tablets) was recently approved in the U.S. for the treatment of idiopathic Parkinson's disease. Requip XL is the first and only oral once-daily non-ergot dopamine agonist indicated for treatment of Parkinson's disease.

Results from a pivotal efficacy and safety trial showed that adding Requip XL to patients' existing levodopa (L-dopa) therapy reduced the amount of "off" time experienced by patients with Parkinson's disease by 2,1 hours per day on average.

Requip XL is an extended-release, once daily tablet formulation that uses a tri-layer formulation for continuous delivery of ropinirole over 24 hours to provide smooth blood levels.

Side effects may include nausea, dizziness, drowsiness or sleepiness, headache, and sudden uncontrolled movements (dyskinesia). Increase or decrease in blood pressure and heart rate may occur. Hallucinations may also occur during treatment. Patients should tell their doctor if they experience new or increased gambling, sexual, or other intense urges while taking Requip XL. ■

10 THINGS EVERY PERSON WITH PARKINSON & CAREGIVER SHOULD DO

PERSON WITH PARKINSON'S

CAREGIVER OF A PERSON WITH PARKINSON'S



Remember the importance of a positive attitude

1

Understand the importance of taking care of yourself



Establish a good relationship with your doctor

2

Realize it is normal to experience a range of feelings such as anger, sadness, loneliness, guilt, resentment

Learn as much as you can about your disease

3

Learn constructive ways to handle emotions; exercise, talk with friends, read a journal, or practice relaxation techniques



Maintain a daily exercise program

4

Practice positive self-talk

Take your medications on time exactly as prescribed

5

Recognize depression and get help for it



Don't let the disease control you-you are the master

6

Arrange to make time for yourself, your interests and friends

Contribute some service to your community

7

Attend support group meetings and talk about your problems

Attend support groups meetings

8

Learn how to face your loved one's physical challenges

Remain as independent as possible for as long as you can

9

Let the loved one do as much as possible while he/she is still able



Live each day to the fullest and never lose hope

10

Deepen your faith and spirituality



The above article was adapted from the one published in the Fall 2007 newsletter of the APDA Deerfield Beach, FL I&R Center.



BY ENRICO FAZZINI, DO, PhD
Associate Professor Neurology
New York University, New York
University of Nevada, Las Vegas
N.Y. Institute of Technology, Old Westbury



Q: I have Parkinson's disease for seven years. I was on the Neupro patch and doing well but it was discontinued. I am still on Sinemet 25/100 three times a day and two Zepalar 1.25 tablets in the morning, but I am very stiff during the night and I get very tired after lunch and cannot move. What can I do?

A: Requip XL is a long acting medication which is similar to Neupro in that it directly stimulates areas of the brain that need dopamine and works smoothly for 24 hours. It can be started as 2 mg a day and increased by 2 mg per week until you reach a therapeutic dose which in most people is 8 mg a day. You should also make certain that you take your Sinemet one hour before meals and keep your proteins (meat, chicken, turkey, pork, fish) low at lunchtime because the protein can interfere with the absorption of Sinemet.

Q: My wife has Parkinson's disease for 15 years. She gets panic attacks during the day and breathes heavy with sweats. This also happens during the night. She takes Sinemet 25/250 and Mirapex 0.5 mg four times a day.

A: There are times during the day when her medications are not working. This is called "wear-off" and in addition to becoming physically slow and stiff, she develops a sense of impending doom or panic. Her

breathing becomes more difficult because her chest wall is getting stiffer and there is a dilatation of blood vessels which makes her sweat. She probably was always anxious or depressed and this has made her more prone to getting these panic attacks. The answer is to change her medications so that it does not wear off. This can be done by increasing the Mirapex dose, lowering the Sinemet to 25/100, adding Comtan and/or selegiline/Zelapar or Azilect and making sure she takes her medications at three hour intervals for example 8 am, 11 am, 2 pm, 5 pm with an 8 pm dose if needed. In addition, it would be beneficial to add an antidepressant so she is not so sensitive to the psychological effects of the erratic absorption of L-DOPA (Sinemet).

Q: I have had essential tremor diagnosed for ten years mostly involving my head. I am 60 years old. Recently I have had right shoulder surgery. The tremor has spread and I feel it throughout my body. I have some slowness in my right arm. My internist said I might have Parkinson's disease but the local neurologist said there are not enough symptoms of Parkinson's disease and he wants me to try propranolol. What do you think?

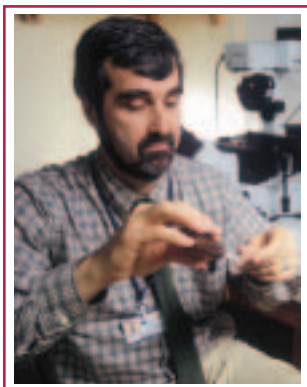
A: The diagnosis of Parkinson's disease is made based on the presence of bradykinesia (slowness of movement) plus either resting tremor, cogwheel

rigidity or walking abnormality such as freezing, shuffling and/or balance impairment. It could be that the tremor you have is with action and the slowness in the right arm may be attributed to the right shoulder surgery. In cases like this we sometimes will use medicines to help us make the diagnosis. If you get much better with propranolol you most likely have essential tremor which has worsened. If you do not get better, Sinemet can be tried and if this works you most likely have Parkinson's disease. Keep in mind that patients with essential tremor may also develop Parkinson's disease so it is also a possibility that you have both conditions. I would agree that propranolol should be tried.

Q: Is there a facility where a PD patient can go and stay overnight or a few days for testing?

A: No. All of the medications are given by mouth and the changes in medication may take days or weeks to have their full effect. The hospital is a dangerous setting for PD patients as medications are often not given exactly according to your schedule and patients may get disoriented and confused. You can ask to be observed over an entire day in the doctor's office so that he/she can better appreciate what you look like when your medicines work too much and/or too little. ■

JAMES P. BENNETT JR., MD, PHD, APDA SCIENTIFIC ADVISORY BOARD MEMBER



Lewis Carroll observed that, "If you don't know where you are going, any road will get you there."

It appears that APDA scientific advisory board member James P. Bennett, Jr., MD, PhD, knew from the start that a career in science was where he was going, with a small detour into medicine.

Winning a high school science fair was the beginning followed by a degree in chemistry from the University of Florida. Medicine, however, was a side road he hadn't considered until a neurosurgeon/neurologist family friend in St. Petersburg described the first patient he put on L-DOPA.

"I was a chemistry graduate student in the late 1960s, and that was before carbidopa, so it was difficult to predict outcomes." Dr. Bennett remembers the doctor reporting that the next morning when he asked his patient how she was doing, and she began to cry tears of joy because she told him that for the first time in 10 years she could brush her own teeth. "I was so impressed with the clinical usefulness of chemistry that I reluctantly went off to Johns Hopkins School of Medicine, but then stayed around and entered grad school to get a Ph.D in pharmacology. So in an unusual way, my career was shaped from the start by Parkinson's disease."

In 1982, while chief neurology resident at the University of Virginia School of Medicine (UVA), APDA recognized him with its fourth Dr. George C. Cotzias Fellowship, its most prestigious award given to a young neurologist to encourage his pursuit of research. That award was to be the first of more than \$7 million (?) in National Institutes of Health grants that Dr. Bennett's work has brought to PD research. APDA has subsequently funded an additional two of his research studies.

In 1990, he was an associate professor of neurology, tenured three years later, and reached full professor status four years later. Today he is the director of the University of Virginia's Center for the Study of Neurodegenerative Diseases as well as the Arthur and Margaret Ebbert Professor of Medical Science.

Dr. Bennett's is one of four labs that form UVA's center where the cause of neuronal death is being sought. UVA is also one of APDA's nine centers for advanced research, and the location of the Virginia Information & Referral Center.

In addition to his hands-on research work, Dr. Bennett is a dedicated mentor of young scientists and has guided more than 30 predoctoral and postdoctoral students, many of whom hold associate and assistant professorships at prestigious academic institutions around the United States and abroad.

Both he and his wife, Donna, love the great outdoors and are active in local conservation and environmental pursuits. Thirteen years ago, for example, they formed an organization to protect a local river. The Bennetts are the parents of two grown sons, Jamie, a copy editor, and Jason, a free-lance Web site designer/photographer. ■

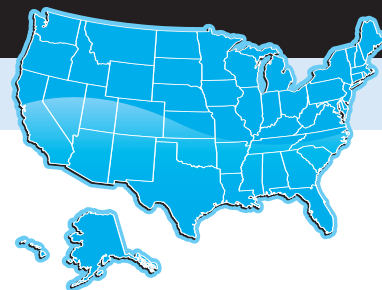
APDA \$50,000 RESEARCH GRANT LEADS TO \$1.3 MILLION NIH AWARD

Once again, an APDA research grant has provided the seed money needed for a young researcher to obtain necessary data leading to a million dollar award from the National Institutes of Health (NIH).

Christopher Bishop, PhD, was awarded the one-year APDA grant for his study, "Dorsal Raphe Regulation of L-dopa Induced Dyskinesia" in 2007.

The five-year, \$1.33 million award from the NIH's National Institute for Neurological Disorders and Stroke will allow Dr. Bishop, who is an assistant professor of psychology at Binghamton (N.Y.) University, and his colleagues at Chicago's Veterans Administration Hospital and Wayne State Medical School, Detroit to study the effects of long-term use of L-dopa on Parkinson's patients, especially dopamine-induced Dyskinesia and other motor fluctuations. ■

FYI. 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 disease and their caregivers across the United States.



IN THE WEST

The West promises to be wild once again - at least for a while – when APDA's San Fernando Valley Regional Chapter co-sponsors the 2008 Ride for A Cure at Gibson Ranch. The five-day ride 'em, rope 'em, penning event will include live music, a stunt show, kiddies' stick horse race, specialty acts and a celebrity team sorting.



San Fernando Valley Regional Chapter secretary Kathy Artis and president Caryle Woolf do a little clowning around during a Fourth of July parade while distributing more than 1,000 flyers to promote the chapter's upcoming rodeo fundraiser.

While the national young onset center is not yet two years old, coast-to-coast activities are presenting educational and social opportunities for hundreds of families. The seventh annual YOPD Retreat in Columbus, Miss., picked in encounter groups, discussions with nationally recognized neurologists, and net-

working, with great outdoor activities including fishing, hiking, and badminton. The Mississippi and Tennessee I&R Centers sponsor the retreat with the Birmingham (Ala.) Chapter. On the West Coast, four coordinators: Linda O'Connor, Martha Gardner, Debbie Baires and Viviane Tondeur are putting the finishing touches to their first Young Onset Parkinson's West Coast Retreat at the Wonder Valley Ranch Resort and Conference Center, in the Sierra Nevada foothills. The two-day event includes daily Parkinson's wellness session with yoga, T'ai chi, music therapy and relaxation techniques and dinner with National Center director Julie Sacks and Arlette Johnson, the

founder of the country's first young onset I&R center. This event, too, offers lots of educational programs and time for outdoor activities including golf, horseback riding, boating, fishing and hiking. More information can be found on the APDA Web site or by calling 866-499-2732.

IN THE SOUTH

Still rebuilding from the devastation of Hurricane Katrina, Mississippi Chapter president Rose Cutter and I&R Center coordinator Brenda Allard have been working tirelessly to rebound. After a successful Pine Belt tulip quilt raffle last

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PROUD HANDS BOOK PROFILES PD HEROES



“Proud Hands Personal Victories with Parkinson's/A Show of Hands,” a 60-page book of personal profiles of people who have not allowed Parkinson's disease to conquer their lives and lifestyles, is being given as a gift to everyone contributing \$15 or more to APDA to help meet its mission. The book was published by Teva Neurosciences to benefit APDA's research efforts and to support people living with the disease, their caregivers and educational programs. Contributions can be made by mail, by calling 800-223-2732 or on the APDA Web site www.apdaparkinson.org. ■

APDA GROWING TO SERVICE THE PARKINSON'S COMMUNITY

Welcome to two new chapters, APDA's awareness and fundraising arms, in Pennsylvania and East Texas. Heather Fritz, a physical therapist, is the president of the Central Susquehanna Valley Chapter in Denville, Penn. Noemi Eva Evans is heading up the new chapter in Tyler, Texas with lots of help from coordinator Kelly Pierson.

It may have taken three years, but the New Orleans I&R Center wiped out by Hurricane Katrina has been relocated. Coordinator Maureen Cook, RN, and medical director Jay Rao, MD, are now at the Ochsner Foundation Clinic.

Two other centers have found new locations in their cities: the University of New Mexico is the new site for the Albuquerque Center with Jeannine Boyle, coordinator and Sara Pirio Richardson, MD, medical director; and Baylor

University Medical Center is the new Dallas site with Kim Wisner, coordinator, and Cole Giffler, MD, the medical director.

Trish Low, RN, is the coordinator in the newly opened Pasadena, Calif. center at Huntington Hospital, and Jerome Lisk, MD, is the medical director.

...ON A SAD NOTE

Fred Dyas, president of the San Antonio Chapter for the past four years, died suddenly on June 13 of a heart attack. Fred was 60 years old, a former educator and grammar school principal, and known as someone who lived with Parkinson's with courage, dignity and a sense of humor. APDA regional representative Joan Duval called him, "someone everyone loved. We will miss him and his wonderful photography." Our sympathies go to his wife Anna Marie and children, Scott, Anne, Mathew and Ashley. ■

AROUND THE COUNTRY *cont. from page 6*

year, they decided to combine two proven successful fundraisers and created, to our knowledge, the first APDA Walk/Rock-a-Thon this year. "It's a challenge," says Brenda, who immediately following the hurricane, distributed flyers in the most devastated areas to let people with Parkinson's know where to find help.



In between storms and starring as a featured subject in Teva Neurosciences book benefiting APDA, "Proud Hands Personal Victories with Parkinson's/A Show of Hands," Iowa coordinator Sam Erwin has been busy raising awareness and funds for APDA. With temperatures in the misty 40s and with a strong wind, she led a brave contingent around the Cedar Lake Trail for its annual walk-a-thon. Despite those aforementioned storms that included floods and power outages, more than 200 people attended the all-day annual conference in West Des Moines. Among the speakers were APDA's national young onset director, Julie Sacks, and Amy Comstock Rick, executive director of the Parkinson's Action Network. ■



Iowans with PD banding together to raising awareness are (l-r) Sam Erwin, Bill Hinkle, LaDonna Molander, Mike Ketcham, Marc Quade and Deb Wityk. Gwen Peterson is seated.

Flower Power for Parkinson's

40% donation to PD research

14th ANNUAL PLANTING DAY

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-34-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 percent of the price (excluding 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.

Flower Power:

1. Order online at www.tulipworld.com/WFOA
2. Call toll free 1-800-888-9997

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100 EAST 17th STREET
DALLAS, TEXAS 75202
TEL: 214-750-1138

the SN. In PD patients' postmortem tissue, and in animal models of PD, inflammatory cells and markers of inflammation such as cytokines are present in the SN where cell death is occurring. In animal models, nonsteroidal anti-inflammatory drugs (NSAIDs) exert a neuro protective effect - slowing or preventing the development of PD.

In a most recent study done at the University of California, Los Angeles (UCLA) researchers evaluated 293 patients with typical PD and compared them to 286 age, race and sex matched control patients without PD. The study looked at the patients' use of aspirin or non aspirin NSAIDs such as ibuprofen (Motrin®, Advil® etc.) or naproxen (Aleve® and others) as well as other prescription NSAIDs. Most patients were using the NSAIDs for arthritis but the aspirin users may have been taking them for stroke or heart attack protection. The results showed non aspirin NSAIDs were protective and lessened PD risk by 50% and the protection increased to 60% diminished risk of PD in those patients taking them for more than two years. The protective benefit was more modest with an approximately 20% reduction in risk of PD in women. For men, aspirin seemed to have no clear benefit in reducing PD risk.

An interesting twist in this picture of cell protection in the SN comes from a study done in New York which evaluated a large number of patients with PD and control patients, and assessed them for behaviors such as drinking coffee regularly, or smoking, as well as use of NSAIDs. In that study, the combination of smoking, coffee use and use of NSAIDs had an 87% reduction in the risk of development PD.

What does this mean for patients who currently have PD? Should they be advised to sit on the patio, have a cup of coffee, smoke a cigarette and take a few Advil? I think not! There are no medical studies to show there is a benefit of slowing the disease progression by taking NSAIDs once you have the disease. These anti-inflammatory drugs do have potential risks since they can cause peptic ulcers and gastrointestinal bleeding and in some patients they can cause kidney or liver damage. Smoking cigarettes has clear health risks. A cup of coffee or two may not hurt and may help combat the daytime drowsiness in PD patients. Protecting the SN cells from slowly and progressively dying off in PD remains a challenge for which we do not have a clear answer.

Cell Replacement

What about replacing the SN cells that are dying in PD? Two prior papers on stem cell research in the last three months are very promising for PD patients. In November 2007 in the journal, *Nature*, the group at Oregon National Primate Research Center reported the successful produc-

tion of a stem cell line in primates (monkeys). This was created by transferring a nucleus from a skin fibroblast into a fertilized monkey egg that had the DNA removed. The resulting stem cell line has neuronal stem cells markers and can become brain cells which could theoretically be used to replace those lost in PD. Other cells were prodded to become heart cells and were observed to be "beating heart cells." This represents a breakthrough since prior to this, primate cells have been impossible to coax into the stem cell state.

The other report also came in November 2007. This one in the journal, *Science*. It was from the laboratory of James Thomson, Ph.D. at the University of Wisconsin, who had created the first line of stem cells from human embryos. The current study is truly a breakthrough for both scientists and ethicists. They identified four genes that reprogram skin cells to become stem cells. The cells they produced are indistinguishable from embryonic stem cells in that they can be given orders to turn into any cell type in the body such as SN cells in PD patients. Since there is no need with this technique for human eggs or embryos, the ethical issues of destroying one life to help another are averted. This was lauded as an advance in "ethical stem cell research" by President Bush.

The new technology, however, uses cancer genes and retroviruses (AIDS-like viruses), both of which may create problems with tumor growth from the newly created stem cells. Needless to say, these safety issues will have to be worked out. To this date, the only successful treatment of PD with stem cells was achieved in a rat model PD in year 2005. ■

This article was adapted from the one published in the Winter 2008 newsletter of the APDA Deerfield Beach, FL I&R Center.

PATIENT ASSISTANCE

An estimated 47 million Americans have no health care coverage.

We have been informed that Novartis, recognizing the need to help these people by providing them with easier access to quality health care has launched the "Patient Assistance Now" program. Such program integrates Novartis and non-Novartis resources to help patients pay for their medicines; learn about specific diseases, conditions and drugs and obtain information about ongoing and planned clinical trials.

People can visit the online Web site, www.patients-assistancenow.com, or call 1-800-245-5356 for specific information about programs and services available.

When And How To Share Your News

By Deborah Dalin Guyer, MA, CCC-SLP,
Coordinator, Saint Louis, MO, APDA I&R Center

I frequently receive confidential calls from newly diagnosed individuals who are seeking information about Parkinson's disease (PD), but wish to remain anonymous or non-involved at this time. We know that PD does not just "happen" to the individual who is diagnosed as having it. It also impacts the family, friends and co-workers who sincerely care about your well-being. Deciding when and how to share the news is based on the dynamics of your relationship and your comfort level in sharing this kind of news.

In Chapter 7 of the recently published book, *Parkinson Disease for Dummies*, by Tagliati, Guten and Horne (Wiley Publishing Inc. 2007), the authors suggest that it is your job to establish the ground rules and indicate what will and will not be helpful for you. Initially you may need people to listen, to distract you when necessary, and to give you the gift of normalcy. Remember, too, that accepting help when it becomes needed, is not a sign of weakness.

An upbeat, optimistic attitude is an effective weapon against PD. As with any health issue, your physical and mental health at the onset of diagnosis can have an enormous effect on the progression of the disease.

Having PD raises many concerns for the spouse or partner of a person living with the condition. Partners too can suffer from anxiety and depression over the unknown future and the risk of disability, job, economic losses and increased dependence. How PD will impact your relationship will depend greatly on the kind of relationship you had before the diagnosis. If you are able to communicate and share your feelings and concern with



each other in a very accepting manner, chances are your relationship can grow stronger. Your partner and you will need to work your way through the questions on how this diagnosis is going to affect your lives—both individually and together. The roles you've settled into may undergo a make-over as your PD progresses. Fortunately, this progression usually occurs over a period of years with ample time to adjust.

Don't rush into changes before they are necessary. Take time to plan the way that you can adjust certain tasks or roles before you give them up. When you decide the time is right to share your news with your immediate and extended family, stick to the basics: what is PD, whether others in the family are at risk, how PD is treated, what your prognosis is. We and other APDA I&R Centers have an extensive library of books, booklets and educational supplements available which can help you in this process.

Most newly diagnosed individuals want to learn how to live with PD without having people feel sorry for them or treat them differently. As with other illnesses, you are still you! Give the people you care about the

chance to love you enough to help.

Remember that your friends may have already noticed your symptoms and discussed their concerns with each other. Friends can listen when you don't really want to burden your partner. And they can take your focus off PD to get you back on the track of living the life you've planned. There are people who play a role in your life, but not a vital or intimate one (neighbors, group associates, professionals.) You needn't feel compelled to break the news to them; however, don't underestimate the resources that may come from one of these people. Set the tone for their responses, correct misinformation they may have about PD and appreciate their concern and support. Over time your PD will become more difficult to disguise. Even if you can manage the outward symptoms, the stress of trying to keep it a secret can drain you.

Finally, the individuals with PD have the right to decide when and how to share the news, how to face the challenge, and how to maintain those facets of their life that were part of their identity pre-PD diagnosis for as long as possible (even if it takes a little longer to do so!) ■

APDA RESEARCH FUNDING

Centers for Advanced Research

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

Cotzias Fellowships

David Hinkle, MD, Ph.D.	University of Pittsburgh <i>Pittsburgh, PA</i>	The Potential Role of Antioxidant Systems in the Mechanism of DJ-1 Dependent Astrocyte-mediated Neuroprotection
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
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 Grant

Andrei Alexandrescu, Ph.D.	University of Connecticut <i>Storrs, CT</i>	Stability and Solvent Accessibility of Alpha-Synuclein Fibrils by NMR Hydrogen Exchange
Jeffrey Stock, Ph.D.	Princeton University <i>Princeton, NJ</i>	Protein Phosphatase 2A Methylation as a Therapeutic Target for Parkinson's Disease
Marc Tatar, Ph.D.	Brown University <i>Providence, RI</i>	Assessing the Pathogenic and Molecular Consequences of FOXO Regulation by Parkin

Post-Doctoral Fellowships

Jason Cannon, Ph.D.	University of Pittsburgh <i>Pittsburgh, PA</i>	Genetic and Environmental Interactions in Parkinson's Disease: Potential for New Therapeutic Pathways
William Caudle, Ph.D.	University of Washington <i>Seattle, WA</i>	Proteomic Analysis of VMAT2 under Normal and Pathological Conditions
Yeun Choo, Ph.D.	Burnham Institute for Medical Research <i>La Jolla, CA</i>	Regulation of Parkin by Neddylation
Stephen Crimmins, Ph.D.	University of Alabama <i>Birmingham, AL</i>	Reduction of Alpha-Synuclein and Neuroprotection Against its Toxicity by Enhancing Proteasome Activities
Gizem Donmez, Ph.D.	Massachusetts Institute of Technology <i>Cambridge, MA</i>	Analysis of the Role of SIRT2 Protein in Parkinson's Disease
Robert Drolet, Ph.D.	University of Pittsburgh <i>Pittsburgh, PA</i>	Gastrointestinal Dysfunction in the Rotenone Model of Parkinson's Disease
Muralidhar Hedge, Ph.D.	University of Texas <i>Galveston, TX</i>	Role of Transition Metals in Inhibiting Repair of Oxidized Bases in Genome: Relevance to Parkinson's Disease
William Lin, Ph.D.	University of Chicago <i>Chicago, IL</i>	Mechanism and Function of Cytosolic PINK1
Zhihui Sun, Ph.D.	University of Pennsylvania <i>Philadelphia, PA</i>	Investigating Synuclein Gene Function In Zebrafish
Daniel Tardiff, Ph.D.	Whitehead Institute for Biomedical Res. <i>Cambridge, MA</i>	Mitochondrial Proteomics of a Yeast Parkinson's Disease Model
Ravindar Thomas, Ph.D.	University of Virginia <i>Charlottesville, VA</i>	Development of Mitochondrial Gene Therapy for Parkinson's Disease
Yulan Xiong, Ph.D.	Johns Hopkins University <i>Baltimore, MD</i>	Modeling LRRK2-Induced Toxicity in Yeast
Nanyan Zhang, Ph.D.	University of Colorado <i>Aurora, CO</i>	Delineating Protein Coaggregation during Lewy Body Formation

Research Grants

Hans Bueler, Ph.D.	University of Kentucky <i>Lexington, KY</i>	Identification of PINK1 Substrates Using Conditional PINK1 Knockout Cells and Quantitative Phosphoproteomics
Ippolita Castelvetti, Ph.D.	Massachusetts General Hospital <i>Charlestown, MA</i>	Biological Basis for Differential Susceptibility to Alpha-Synuclein Pathology in the Male and Female Human Brain
Savio Chan, Ph.D.	Northwestern University <i>Chicago, IL</i>	Sriatopallidal GABAergic Signaling in Mouse Models of Parkinson's Disease
Linan Chen, MD, Ph.D.	University of Chicago <i>Chicago, IL</i>	Transgenic Overexpression Selectively in Dopamine Neurons via Controlled Genetic Amplification
Shu Chen, Ph.D.	Case Western Reserve University <i>Cleveland, OH</i>	Transgenic C. Elegans Model of LRRK2-Linked Parkinson Disease
Shankar Chinta, Ph.D.	Buck Institute for Age Research <i>Novato, CA</i>	Potential Neuroprotective Role of Resveratrol in Parkinson's Disease Mouse Models
Paul Davenport, Ph.D.	University of Florida <i>Gainesville, FL</i>	Central Neural Gating of Pharyngeal Mechanically Elicited Cortical Evoked Potentials (CEP): An Evaluation of Swallow Neural Integration in Parkinson's Disease (PD)

FOR FISCAL YEAR 2008-2009

Research Grants *(continued)*

Wei Ming Duan, MD, Ph.D.	Louisiana State University <i>Shreveport, LA</i>	Generation of Dopaminergic Neurons from Endogenous Stem Cells in the Brain of a Mouse Model of Parkinson's Disease
Jian Feng, Ph.D.	State University of New York <i>Buffalo, NY</i>	Generating Patient -Specific Induced Pluripotent Stem Cells to Study Parkinson's Disease
Matthew Goldberg, Ph.D.	UT Southwestern Medical Center <i>Dallas, TX</i>	Parkin, DJ-1 and Glutathione Peroxidase-Deficient Mouse Models of PD
Steven Johnson, MD, Ph.D.	Portland VA Research <i>Portland, OR</i>	Redox Regulation of NMDA Currents in Midbrain Dopamine Neurons
Shubhik Kumar, Ph.D.	Lake Forest College <i>Lake Forest, IL</i>	A Study of Autophagic Regulation of Alpha-Synuclein Toxicity in Yeast
Darren Moore, Ph.D.	Johns Hopkins University	Dopamine Neuron-Specific Accumulation of Mitochondrial DNA Mutations in Mice
Gerardo Morfini, Ph.D.	University of Illinois <i>Chicago, IL</i>	Molecular Mechanisms Underlying MPP+ Induced Activation of Cytoplasmic Dynein-Based Vesicle Transport
Anthony Nicholas, MD, Ph.D.	University of Alabama <i>Birmingham, AL</i>	Gene Analysis of Histone Deacetylation in Levodopa-Induced Dyskinesia and Priming
Arnulfo Quesada, Ph.D.	Brentwood Biomedical Research Institute <i>Los Angeles, CA</i>	A Promising New Protective Factor for Parkinson's Disease
Hardy Rideout, Ph.D.	Columbia University, <i>New York, NY</i>	Modification of LRRK2 Oligomerization and Neurodegeneration by 14-3-3
Jean Rochet, Ph.D.	Purdue University <i>West Lafayette, IN</i>	Role of ATP13A2 (PARK9) Dysfunction in Parkinson's Disease
Subhojit Roy, Ph.D.	University of California <i>Jolla, CA</i>	Effects of Alpha-Synuclein on Fast and Slow Axonal Transport
Derek Siebruth, Ph.D.	University of Southern California, <i>Los Angeles, CA</i>	Large Scale Analysis of Synaptic Architecture in Alphasynuclein Expressing Neurons
Wanli Smith, MD, Ph.D.	Johns Hopkins University School of Med. <i>Baltimore, MD</i>	Autophagy and LRRK2-Linked Parkinsonism
Shaji Theodore, Ph.D.	University of Alabama <i>Birmingham, AL</i>	Inhibiting Nuclear Factor Kappa B Signaling and Microglial Activation in a Mouse Model of Parkinson's Disease
Enrique Torre, Ph.D.	Emory University <i>Atlanta, GA</i>	Significance of mRNA Transport and Translation within the Dopaminergic Axon
Kala Venkiteswaran, Ph.D.	Penn State Hershey College of Medicine <i>Hershey, PA</i>	Transplantation of Transdifferentiated Dopaminergic Neurons Derived from Human Retinal Pigment Epithelial Cells
Harrison Walker, MD	University of Alabama <i>Birmingham, AL</i>	Bilateral Clinical and Neurophysiological Effects of Unilateral STN DBS in PD
Gaofeng Wang, Ph.D.	University of Miami <i>Coral Gables, FL</i>	The Role of miRNA in Olfactory Deficit of Parkinson's Disease
Andrew West, Ph.D.	University of Alabama <i>Birmingham, AL</i>	Development of Cell Based Kinase Assays for LRRK2
Kui Xu, MD, Ph.D.	Massachusetts General Hospital <i>Boston, MA</i>	Neuroprotection by Urate in Cellular Models of Parkinson's Disease
Fu-Ming Zhou, MD, Ph.D.	University of Tennessee <i>Memphis, TN</i>	An Ultra Short Dopamine Pathway: Part II. Signaling Mechanisms
Jianhui Zhu, Ph.D.	University of Pittsburgh <i>Pittsburgh, PA</i>	ATP13A2 and Autolysosomal Pathology in Parkinson's Disease
Xiongwei Zhu, Ph.D.	Case Western Reserve University <i>Cleveland, OH</i>	Role of Impaired Mitochondrial Dynamics in Mutant LRRK2 Induced Toxicity

Medical Student Fellowships

Omar Atassi	Johns Hopkins University, <i>Baltimore, MD</i>
Anthony Burrows	University of Massachusetts Medical School, <i>Worcester, MA</i>
Ephraim Church	University of Pennsylvania School of Medicine <i>Philadelphia, PA</i>
Jennifer Kosty	University of Pennsylvania School of Medicine <i>Philadelphia, PA</i>
Neena Marupudi	Penn State College of Medicine <i>Hershey, PA</i>
Jennifer O'Malley	University of Cincinnati <i>Cincinnati, OH</i>

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling 1-800-223-2732, faxing to 1-718-981-4399, or contacting any of the 62 APDA Information and Referral Centers throughout the United States.

BOOKLETS

1. **Basic Information about Parkinson's Disease Brochure** (English)
 2. **Parkinson's Disease Handbook** - Symptoms, causes, treatment - (English, German, Italian)
 3. **Be Active** - An exercise program for people with Parkinson's disease recently published by the American Parkinson Disease Association. This comprehensive educational booklet was written by Terry Ellis, PT, PhD, NCS, Tami Rork, PT, MSPT and Diane Dalton, PT, DPT, OCS of the Center for Neurorehabilitation, Sargent College, Boston University. - (English)
 4. **Be Independent**- Equipment and suggestions for daily living activities - (English)
 5. **Speaking Effectively** - Speech and swallowing problems in Parkinson's disease - (English)
 6. **Good Nutrition** - (English)
 7. **Young Parkinson's Handbook** - (English)
 8. **Aquatic Exercise for Parkinson's Disease** - (English)
 9. **My Mommy Has PD... But It's Okay!** - booklet for young children. (English)
- The Next Step After Your Diagnosis: Finding Information and Support** - It can be obtained by calling 800-358-9295 and requesting booklet AHRQ Publication No. 05-0049

SUPPLEMENTS

The Family Unit; Hospitalization of a Parkinson Patient; Fatigue in PD; Healthy Aging; Keys for Caregiving; Medications to Be Avoided or Used with Caution in PD; Neuro-ophthamology and PD; Medical Management of PD and Medications Approved for Use in the USA and others.

BROCHURES

1. **Basic Information** (English, Spanish, Chinese)
2. **How To Start a Support Group** (English)
3. **National Young Onset Parkinson Disease** (English)

DVD'S

Managing Parkinson's - Straight Talk and Honest Hope, 2nd Edition

Created by the Washington State Chapter of APDA for newly diagnosed Parkinson's patients and their loved ones.

"Next Step After Your Diagnosis/Tips for Taking Medication Safely" - DVD No AHRQ 07-M025 can be obtained, free of charge, from the Agency for Healthcare Research and Quality by calling 800-358-9295, or 888-586-6340 (hearing impaired only) or by e-mailing www.ahrq.gov

WEB SITES

www.apdaparkinson.org for APDA I&R Centers, Chapters, Support Groups, education and information material, meeting dates, medical abstracts, clinical trials and research application guidelines.

www.wpda.org. A weekly updated source of world news from the website from the World Parkinson Disease Association

Materials concerning 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.