

## APDA-FUNDED RESEARCH YIELDS PARKINSON'S DISEASE VARIATION DATA

A 2007 APDA post-doctoral fellowship awarded to Allison Wright Willis, MD, an assistant professor at Washington University, St. Louis, has led to the publication of major data on the geographic and ethnic variations of Parkinson's disease (PD) in the United States.

Dr. Wright Willis's findings, published this year in the journal *Neuroepidemiology*:

- PD rates are highest in the Midwest and Northeast regions of the United States.
- White men have up to double the PD rate than Black or Asian men
- 1.6 percent of the U.S. population age 65 and older is affected
- Approximately 130,000 people are newly diagnosed each year.

*continued on page 10*



*Midwest Chapter President Maxine Dust presents a \$50,000 research check to Dr. Un Jung Kang, director of the University of Chicago's Parkinson's Disease and Movement Disorder Center, and member of the APDA Scientific Advisory Board. The university is one of nine APDA Centers for Advanced Research.*

## HALLUCINATIONS AND PSYCHOSIS IN PARKINSON'S DISEASE

*By Dag Aarsland, MD*

Psychotic symptoms in Parkinson's disease (PD) include visual-perceptual symptoms such as visual hallucinations (VH), illusions, passage and presence phenomena. Hallucinations may also occur

from other modalities, mainly auditory, but usually in combination with VH. In addition, thought disorders, typically delusions may occur. Psychotic symptoms may be mild or severe, occur together or

single, be accompanied by affective and behavior disturbances and require psychiatric hospitalization.

### *Epidemiology*

Psychotic symptoms

are a frequent occurrence in PD. The frequencies vary according to the definition used. If mild forms are included, psychotic symptoms may affect up to 50 percent of patients. Studies on psychosis have mostly focused on visual hallucinations, the most common type of psychotic symptom in PD. Hallucinations, however, can occur in all sensory domains and delusions of various types are also relatively common. Relatively few longitudinal studies of the course of PD exist.

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## PRESIDENT'S MESSAGE

### Dear Reader:

Every year at about this time, I am overwhelmed with the activities of our national organization and the results from the efforts of the people who comprise our network. Chapter members and Information & Referral coordinators working with thousands of support group participants spark an excitement that leads to awareness efforts, walk-a-thons and spring fundraising events limited only by their imagination. Across the United States, from Maine to California and Florida to Washington, tens of thousands of people walk, run, dance, dine, play golf, tennis and volleyball, sell flowers, cruise, and even have gerbil races to raise funds and awareness for Parkinson's disease (PD).

No other organization serving America's 1.5 million people with PD, their caregivers and families can rally the small army known as the American Parkinson Disease Association.

In our quantitative-oriented society, we tend to measure everything with numbers: how many proclamations; numbers of walkers, runners, and golfers; proceeds from luncheons, fashion shows, and galas. And, don't misunderstand me, the funds we raise and provide to scientists and institutions make all the difference in their ability to search for the cause(s) and cure at the core of our mission.

There are, however, so many immeasurable and even unknown-to-us benefits that people derive from our programs. For instance, the patient at a walk-a-thon who receives a give-away device that helps him write more legibly; the caregiver who learns at a lecture about a stress-reduction method that will help her cope better; the patient's grown child who discovers at a conference that her father's apathy may be caused by a new non-motor PD disturbance and becomes more



*Queens (N.Y.) Borough President Helen Marshall, left, receives an APDA pin from Chairman Miele before a Parkinson's Awareness proclamation ceremony. With them is Bea Cordero, RN, Far Rockaway, N.Y. I&R coordinator.*

tolerant. And no one can measure the almost spiritual uplifting created at an event with hundreds of people rallying to the cause, or seeing one's governor, mayor or congressman proclaiming appreciation for those who are fighting to eradicate a progressive degenerative disease. They are the unheralded personal benefits that don't show up on balance sheets or activity reports, but are at the very core of true service.

While we tend to credit Mother Nature for spring's rekindling of hope, at APDA we know that in the Parkinson's community, a great deal of credit goes to you who support our efforts. Thank you.

Joel A. Miele Sr., PE  
President

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*Materials concerning Parkinson's disease research and answers to readers' questions are solely for information and should not be used for treatment purposes, but for discussion with the patient's health care provider.*

**Q:** Does Parkinson's disease affect the eyes and if so, how?

**A:** Parkinson's disease can have several effects on the eyes. The most common problem is dry eyes, which is caused by the reduced rate of blinking in PD. The normal rate of eye blinking is around 10 times per minute. Persons with PD blink much less, leading to drying of the cornea, itching, pain, and redness. This is particularly common in hot and dry weather. This can often be treated with artificial-tear eyedrops, but they must be used frequently for a week or more to correct the problem, and then continued as a preventative measure in those prone to dry eyes.

A less common eye problem related to PD is double vision. This appears most often when looking quickly from one place to another. Double vision is a reason to see an ophthalmologist, to be certain that it is not due to a problem with the eyes or lenses, but it often turns out to be caused by the effects of PD on eye movements, so that one eye moves a bit slower than the other at times. It is often hard to find a solution to this problem, aside from covering one eye when it is troublesome, but the good news is that it is generally mild and does not progress much over time.

A third effect of PD on the eye is on color vision. This is usually not noticed by persons with PD, but can be detected by sensitive vision tests. It is of interest to scientists studying PD because the eye has dopamine neurons, and it is thought that changes in color vision may be a marker for other effects of PD on dopamine cells.

**Q:** What is the risk of a family member acquiring Parkinson's disease?

**A:** This is a common question – nearly everyone with PD wonders if it will affect his/her children. The answer for the most part is no – the risk of a family member acquiring PD is no greater than anyone else. It is important to remember that PD is a common disease

– more than one in 100 people over age 65 are affected by it, so there will be families in which several members are affected simply by “bad luck.”

There are some exceptions to the general rule that PD does not run in families. Studies in the past several years have shown that there are

some inherited forms of PD, and the discovery of the genes responsible has led to very important advances in research. Still, all the genes discovered so far account for only a small number of cases of PD, less than 2 percent of the total.

How can you tell if one of these rare genes for PD might run in your family? If there are many family members across several generations affected, it is possible that your family carries one of the “dominant” mutations for PD. Generally this should be considered when there are four or more blood relatives who all have PD.

Another circumstance in which an inherited form of PD is possible is early onset. When the symptoms begin before the age of 40, there is a good chance that it is caused by one of the “recessive” genes for PD. The odds are even higher when the onset is before the age of 20 (which is a very rare event).

It is possible to perform genetic tests for some of the inherited forms of PD, but in most cases this is not necessary. The treatment for the genetic forms is the same as for other kinds of PD, so a genetic test is not helpful in choosing medications. Genetic tests can also be misleading, since not all the genetic forms can be tested for. Genetic tests are also expensive. If you are considering a genetic test for PD, you should discuss this carefully with your doctor and consider whether the information will really be helpful to you. Don't do it “just to find out!” ■



**DAVID G. STANDAERD, MD, PhD**  
Director Center for Neurodegeneration and Experimental Therapeutics, University of Alabama at Birmingham and Member of the APDA Scientific Advisory Board.

## HALLUCINATIONS AND PSYCHOSIS IN PARKINSON'S DISEASE

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Psychotic symptoms, however, once present, tend to be persistent and progressive.

### **Clinical presentation**

The typical VHs consist of persons, who may or may not be familiar, and less often animals or objects. They may be numerous, but often single or few in numbers. They are usually complex, and stereotype in a given patient. They appear suddenly, often move, and usually seem very real. They usually vanish suddenly, sometimes when the patients try to ascertain their reality by approaching or touching them, or asking other people to confirm their presence. They often occur in dim light, often at night. Insight into the pathological nature of the phenomenon may or may not be present. Lack of insight is more common in subjects with cognitive impairment.

Capgras delusion (a friend, spouse, or close family member has been replaced by an identical-looking impostor) and similar misidentification phenomena may also occur. Typically, the patient thinks that a spouse is someone else which may create challenging situations with affective and behavioral changes. Other forms of delusions are relatively rare, but are often persecutory, or focus on infidelity.

The neuropsychiatric symptoms in PD tend to cluster into distinct syndromes. In a recent study, five clusters were identified. The largest groups showed symptoms of mild depression, followed by a group with hallucinations and mild other symptoms.

One group had sleep disturbances exclusively, and another showed apathy, anxiety and depression. A small group showed a variety of severe symptoms, including psychosis and agitation.

### **Assessment and diagnosis**

Recently, consensus criteria for PD-associated psychosis were proposed after an NIH-sponsored workshop. Psychotic symptoms, however, are not always reported voluntarily, and the clinician should ask for these phenomena. Some patients may deny or refuse to report these symptoms, or, in dementia, may have forgotten, and thus a caregiver should be questioned as well. The frequency, intensity and impact of the symptoms should be noted, as well as the situation and circumstances in which they occur, the detailed phenomenology, and any other accompanying symptoms such as cognitive impairment, depression, anxiety, and sleep disorders. There are several rating scales in use, although no generally accepted ones.

### **Etiology**

Psychotic symptoms develop from a complex interplay of extrinsic and intrinsic factors. It was previously considered that VHs in PD were caused by the dopaminergic medication. It is now generally accepted, however, that although dopaminergic drugs - in particular dopamine agonists - can contribute to the emergency of psychosis, other factors may be more important, such as dementia and visuospatial (thought process that involves visual and spatial awareness) impairment, as well as general factors such as old age and more advanced disease stage. Brain changes found to be associated with an increased risk for psychotic symptoms in PD include cholinergic deficiencies and Lewy bodies in the temporal lobe. Pathological excitation of the visual pathways caused by physical or chemical factors may contribute.

### **Clinical consequences**

The impact of psychosis is substantial in that it is associated with dementia, depression, earlier mortality, greater caregiver strain, and nursing home placement. Thus, it is crucial to identify these symptoms in order to optimize the management of PD patients.

*continued on page 11*

## Mirapex Once-Daily Tablet Receives FDA Approval

Mirapex ER (pramipexole dihydrochloride), a Boehringer Ingelheim Pharmaceuticals once-daily Parkinson's disease medication, has received U.S. Food and Drug Administration (FDA) approval. The extended-release tablets are used for idiopathic PD symptoms in early and advanced PD.

The approval, based on data from a randomized, double-blind, placebo-controlled trial, demonstrated both significant symptom improvement, and increased number of hours which advanced PD patients showed better mobility. ■

## APDA FUNDS STUDENT SUMMER FELLOWSHIPS

APDA's summer fellowship provides a stipend to enable medical students to perform supervised laboratory or clinical research designed to clarify the understanding of Parkinson's disease (PD). The program's objective is to encourage future clinicians to consider research as a possible career path.

Applications are reviewed by APDA's Scientific Advisory Board, which this year recommended four fellowships of \$4,000 each to:

- Grant Aaker, Weill Cornell Medical College, project title: "Detection of Retinal Changes in PD with Optical Coherence"

- Shivkaj Bhosle, Burke Medical Research Institute/Weill Cornell Medical College, project title: "Region Specific Regulation of Gene Expression in Dopamine Neurons"
- Nirmish Singla, University of Michigan Medical School, project title: "Evaluation of Lead Placement in Deep Brain Stimulation with Post-op Cognitive and Behavioral Outcomes"
- Minhong Yu, University of Virginia, project title: "Rhythmic Perception in Parkinson Disease."

Students will perform their research project under the sponsor's direct supervision in either a laboratory or clinic setting. ■

## APDA'S DEDICATED CENTER PROVIDES VETERANS' UPDATES

APDA's Dedicated Veterans Information & Referral Center provides free educational materials and programs, support groups, a newsletter, a lending library, general information and support to America's armed forces and their families.

Following are some updates from the center:

- The recently signed Veterans' Emergency Care Fairness act of 2009 enables the Department of Veterans Affairs (VA) to reimburse veterans enrolled in VA healthcare for the remaining cost of emergency treatment if the veteran has outside insurance that covers only part of the cost.

- Vietnam veterans with Parkinson's disease should file claims now with the VA for disability compensation. Veterans eventually found eligible for disability pay will be able to receive compensation back to the date their claim was filed.



- The VA is expanding access to benefits for approximately 500,000 veterans who were pre-

viously precluded from receiving benefits because of income limits set in 2003. The VA began registering Priority Group 8 Veterans in July 2009.

- Lowe's military discount is now year-round. The home improvement retailer has expanded its 10 percent military discount to all day, every day, for active-duty, National Guard and reservists, retiree and disabled service members and their families. ■

For more details and updates contact coordinators Susan Gulas, RN, MSN and Laurel Lindstrom, RN, MS, at 800-223-2732, via e-mail [susan.gulas@va.gov](mailto:susan.gulas@va.gov) or [laurel.lindstrom@va.gov](mailto:laurel.lindstrom@va.gov) or visit the Web site [www.reno.va.gov/parkinsons/parkinsons.asp](http://www.reno.va.gov/parkinsons/parkinsons.asp).

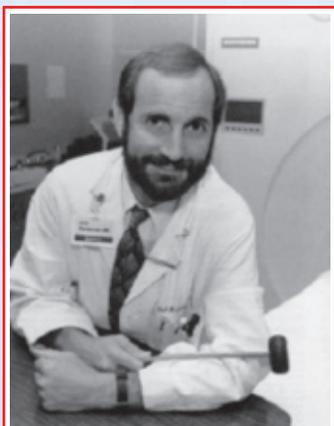
## CoQ10 Study Currently Recruiting Volunteers

A Phase III study to evaluate the safety and effectiveness of high dosages of Coenzyme Q10 in slowing clinical decline in people with early Parkinson's disease (PD) is seeking volunteers. Weill Medical College of Cornell University is the sponsoring institution in collaboration with the National Institute of Neurological Disorders

and Stroke and the University of Rochester.

Male and female volunteers must be 30 years and older, PD diagnosed, not taking any PD medication, and have the presence all three PD cardinal features (resting tremor, bradykinesia, and rigidity). Participants will be randomly assigned to receive a placebo or CoQ10. ■

# APDA Scientific Research and



*Joel Perlmutter, MD, APDA  
Center for Advanced Research  
Director and I&R Center  
Medical Director*

St. Louis's Gateway Arch on the Mississippi River is part of the Jefferson National Expansion Memorial the city's iconic image. St. Louis has numerous other claims to fame, from its Cardinals and Rams, toasted ravioli and Ted Drewes' frozen custard, to some of the country's most renowned museums and zoos in beautiful Forest Park. For people with

Parkinson's disease, however, St. Louis is home to hope through research and comfort via APDA's Greater St. Louis Chapter, Information & Referral (I&R) Center, and Center for Advanced Research at Washington University (WU).

WU has been one of nine such distinguished cen-

ters since 1998. Under the direction of Joel Perlmutter, MD, a pioneer in neuroimaging, head of the university's school of medicine's movement disorder section, and medical director of the I&R center, the center is recognized for its progress in PD research.

With a staff of 18 MDs and PhDs, a doctor of occupational therapy, and a mathematician, the center includes scientists whose findings recently have been funded by the National Institutes of Health (NIH) and published in prestigious journals. Among them are the research results of Dr. Gammon Earhart on dancing's ability to improve functional mobility, Dr. Allison Wright Willis's identification of racial and geographic variants of the disease, and Dr. Brad Racette on the environmental etiology of the disease. Dr. Perlmutter's early studies of the brain's interior using positron emission tomography (PET) have become the benchmark in today's more accurate and earlier PD diagnoses.

A major portion of the center's work, which has recently received two new NIH grants, is toward understanding various aspects of deep brain stimulation. Genetic factors that may contribute to PD are also being

# Patient Support Meet in St. Louis



*Matt LaMartina, Greater St. Louis Chapter president*

studied. And a totally St. Louis Chapter-funded study investigating the relationship of dementia with PD is in its fourth year.

The close working relationships among the chapter, headed by Matthew (Matt) LaMartina; the I&R center, staffed by coordinator Debbie Guyer; and the advanced center are the cornerstone for their success. Dedicated staff and volunteers work on two major annual fundraisers – the Nat Dubman Memorial Golf

Tournament, with Cardinals general manager John Mozeliak as honorary chair, and the annual fashion show, luncheon, and auction with local media celebrities, The

golf tournament and fashion show typically raise more than \$50,000 each to fund patient services and PD research each year.

In addition, Debbie coordinates a dozen support groups across Missouri and southern Illinois and weekly exercise classes at eight different sites. Other programs include respite care – both in home and adult day care, Lifeline and Parkinson's Educational Programs (PEP) with periodic lectures by eminent experts in PD specialties. The chapter also produces a newsletter and maintains a Web site, [www.stlapda.org](http://www.stlapda.org). ■



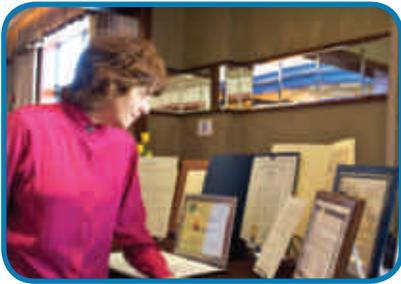
*Debbie Guyer, St. Louis I&R Center Coordinator*

**Below: Washington University, St. Louis**



# APDA AT WORK AROUND THE COUNTRY

PD awareness and walking to raise money for research were the key activities for APDA chapters, I&R centers and support groups across the country during Parkinson's Awareness Month.



*Before the annual spring conference, chapter president Vicki Collier admires the exhibit of 29 proclamations issued by every county, numerous cities and the governor of New Jersey.*

## New Jersey

Vicki Collier led the New Jersey Chapter's efforts and was responsible for proclamations from each of the state's 21 counties, seven cities, and the big one itself, from Gov. Chris Christie. Vicki, I&R co-

ordinator Elizabeth Schaaf, and their loyal volunteers also sponsored a conference attended by approximately 200 people, and featuring producer, author and PBS-TV anchor Dave Iverson, who has appeared at numerous APDA conferences.



*They are off and running in Mississippi's inaugural "Moving Toward a Cure" charity 5K run, 5K race walk, and mile fun run in March.*

## Mississippi

Mississippi entered the race arena with a bang and something for everyone. Chapter president Teresa Jones and I&R coordinator Brenda Allred with the help of chapter members

and many volunteers, launched "Moving Toward a Cure" that included a 5K walk, a 5K race walk, and mile fun run, followed by the Parkinson's Forum at which Dr. Lee Voulter and members of the Movement Disorder Society participated in a roundtable discussion with audience participation. The event raised \$14,000 for research, and looks like an annual event. As an encore, Brenda was interviewed last month on WVBG in Vicksburg.

## New York

Westfield I&R coordinator James Fischer received a commendation from the Mayville (N.Y.) county legislator Fred Croscut during the February meeting. Jim was diagnosed with PD the same year that he retired after two decades as a county child protection investigator, and founded the Parkinson's Association of Chautauqua County, which became an APDA I&R center at Westfield Hospital last year. In addition to the county commendation, Chautauqua's Veteran's Service Agency Director Troy Smith added a commendation for his work helping Vietnam veterans with PD when there were no resources for them locally.

## Texas

Texas is a big state, but Lubbock I&R coordinator Jo Bidwell isn't intimidated when raising awareness about PD is involved. She drove to address groups in Austin one day, Waco the next, and returned to Lubbock the following day for a total of more than 1,000 miles. Meanwhile, farther south the San Antonio Chapter, led by its new president Donald Robin, PhD, was having a media blitz with a press conference that resulted with stories in three media including the Spanish language La Prensa San Antonio. ■

40% donation to PD research

## Flower Power for Parkinson's

Help APDA in the fight against Parkinson's disease. Make a visible statement and a **40 percent 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 20-24-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 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 October 1, 2010.

Two ways to order:

1. Order online at [www.tulipworld.com/APDA](http://www.tulipworld.com/APDA)
2. Call toll free 1-866-688-9547







Tulipworld guarantees the quality of its bulbs and assumes all responsibility for delivery. Packages will be sent in October. Fresh flowers every day. [www.tulipworld.com](http://www.tulipworld.com) To save the tulip, help the cure. [www.apda-usa.org](http://www.apda-usa.org)

# SEXUALITY, INTIMACY AND PARKINSON'S DISEASE

By Kristoffer Rhoades, Ph.D

Most people familiar with Parkinson's disease (PD) are aware of the movement and motor symptoms that classify this as a neurological condition, other prominent and all-too-frequent symptoms, however, are discussed less often. These include depression, anxiety, behavioral disturbances and personality changes. Rarely discussed are the changes in sexual functioning and intimacy that frequently accompany PD.

As many as 68 percent of men and 88 percent of women with PD experience decreased libido, problems with sexual functioning and a sense of decreased intimacy with their partner. A smaller, but still significant percentage experience increased sexual behavior that can be incredibly disruptive and difficult to talk about. Despite these staggering figures, the barriers to discussing these problems persist, including lack of quality research in the area, taboos about sexuality in the elderly and those with a neurological disease, and feelings of discomfort when talking about difficult topics.

There are many factors that may lead to changes in intimacy and sexuality in couples dealing with PD. Among the main predictors of sexual dysfunction and declines in perceived intimacy are increased age and severity of the disease and its symptoms, including motor impairments such as rigidity and tremor that can lead to impaired mobility in bed. There may also be changes in appearance such as sweating, drooling, changes in body odor caused by the disease or medications, as well as gait disturbance. Facial masking and decreased expressiveness may make it difficult to read affection and desire.

Sleep disturbances may lead to bed separation, thus making intimacy less spontaneous and frequent. It should be noted that previous sexual problems and depression are also two of the major factors that impair intimacy and function, as are the presence of other health conditions, such as diabetes and heart problems. As if all of these things weren't enough, both those with PD and their caregivers typically experience significant fatigue and changes in roles that disrupt the usual patterns and venues for intimacy.

So what can couples do to begin to reclaim the intimate parts of their relationships?

The first step is attempting to clarify your concerns and feelings in your own mind and then talking about them with your partner. Recognize and address the emotional stresses of the illness, care giving, and care receiving. A good place to start may be to spend some time thinking about the following questions: What do I need? What do I want? What's missing? What's working?

A frequent and sometimes sizeable barrier to discussing intimacy and sexuality can be our own internal discomfort with the topic. There may be internally held beliefs that "good boys and girls don't talk about these things." Rest assured that they indeed do.

The anticipatory anxiety and fears of discomfort are often worse than any actual embarrassment that may arise when partners find the courage to begin the conversation. Clarifying some of these issues in your own mind may be a helpful first step in getting the conversation between you started.

Once you've begun this internal clarification process, start talking with your partner. Communication is critical! This cannot be overstated.

One of the most essential ingredients is listening. Learn how to listen actively and effectively – there's a clear distinction between listening and waiting to talk. Avoid "mind reading" or assuming what your partner means before he/she has fully expressed him/herself. Don't be afraid to check in and make sure you understand your partner fully before you respond. Learn or rediscover what makes you and your partner feel heard and validated when you are talking. Talk frankly and openly about sexual and intimacy needs. Be clear about what you want, what you need, and what will suffice if you can't have those exact things. It may also be beneficial to identify and then relax your expectations on time limits for communication.

Part of your discussions should include what defines intimacy. Many people think of intimacy and sex as the same thing, but there are important ways that couples can experience intimacy without intercourse. Find other ways to be close to one another that de-emphasize sexual intercourse. Talking openly and honestly about what matters and even talking about your fears and

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## APDA-Funded Research Yields Parkinson's Disease Variation Data

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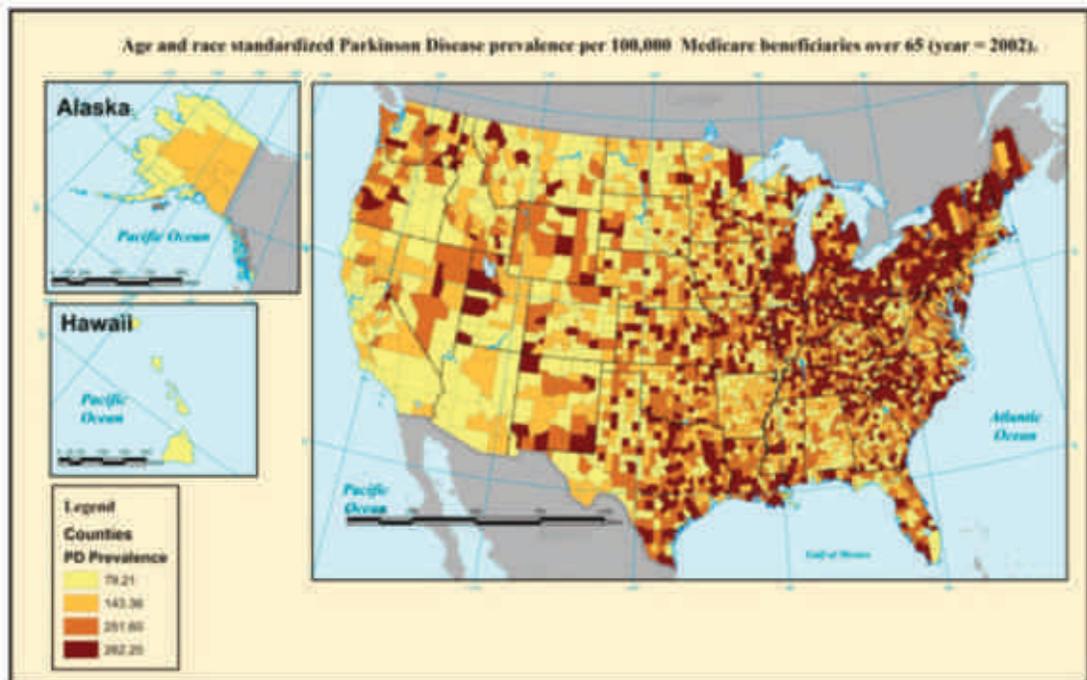
Dr. Wright Willis notes that several interesting theories are suggested by her study including that Blacks and Asians are somehow less susceptible to PD, either because of a protective genetic factor, or decreased exposure to key environmental factors. She also suggests that the geographic preponderance in the Midwest and Northeast supports previous research suggesting that environmental factors (pesticides or metals) may be a contributing cause in non-hereditary PD. The study also confirmed previous data that men

are slightly more likely to have the disease with a 155 men with PD for every 100 women. Asian women had the lowest PD rate in the country.

The study provides large-scale data on PD incidence using Medicare data, the most inclusive popu-

lation-based U.S. health care database spanning a decade. ■

**Dr. Wright Willis's clinical areas of expertise include treatment of adults and children with movement disorders. Her main area of research is the environmental epidemiology of PD.**



*Dr. Wright Willis's research shows a marked propensity of PD in northeastern and midwestern states.*

## SEXUALITY, INTIMACY AND PARKINSON'S DISEASE

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concerns can be intimate. Demonstrate love, respect, warmth and togetherness in non-sexual ways, such as holding hands or each other. Kissing and caressing are often where couples begin – revisit this with a newfound curiosity and sense of openness. If sexual intercourse is possible, experiment with different routines such as lovemaking in the morning. As difficult as it may be, the desire to break out of the old routines and adapting to your new challenges are the most important ingredients for redefining and rediscovering intimacy.

After you've begun the conversation with each other, it's time to talk to your doctor about treatments, effects of medications, and possible referrals to a specialist or a counselor, if needed. Keep in mind that not all interventions will work for every individual, every relationship, or every situation. Again, perhaps the most critical

intervention is to maintain your curiosity and willingness to keep looking for answers, as well as your ability to keep talking with each other.

In addition it will be critical for you and your partner to keep working toward solutions, repeating the same conversations and experiments as necessary. Acceptance of where you are and "what is" will be important, as will be the need to shift your focus from "what you can no longer do" to "what you can still do." ■

**Dr. Rhoades is on the staff of Virginia Mason Medical Center Department of Physical Medical and Rehabilitation, Seattle.**

*Reprinted from the Summer 2009 issue of APDA's Washington State Information & Referral Center newsletter "Parkinson Pathfinder."*

## HALLUCINATIONS AND PSYCHOSIS IN PARKINSON'S DISEASE

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### **Management (Non-pharmacological)**

Psycho-educative approaches, such as information and guidance about the nature of the phenomena may help, as well as cognitive approaches such as distraction or redirecting attention. Environmental interventions such as improving light conditions and visual aids may also be useful. Searching for potential contributing medical factors is always important, such as pain, infection, dehydration, metabolic disturbances, sensory deficits, and recent changes in medication.

### **(Pharmacological)**

First line is always to attempt adjustment of the antiparkinsons treatment. Reduction of dose or number of drugs may reduce the symptoms, even without worsening of motor symptoms. According to expert opinion, anticholinergics should be withdrawn first. It is usually recommended to withdraw selegiline, amantadine and dopamine agonists before changing the levodopa dosage.

The only adequately tested drug to recommend is clozapine, which has been shown to improve VH without worsening motor symptoms. Randomized placebo-controlled trials, however, have been conducted in

patients without dementia only. The risk of agranulocytosis necessitates regular blood tests. Other antipsychotic agents such as risperidone and olanzapine, are less useful, because they are less effective and have a higher risk for adverse events including motor worsening, cognitive decline, and drowsiness and confusion. Initial open-label reports on quetiapine were promising, although two placebo-controlled trials were negative. More novel antipsychotics, such as ziprasidone and aripiprazole, have not yet been tested systematically and preliminary reports are inconclusive. Careful monitoring is required, and dosing should be low with small increments. Recent reports have highlighted that antipsychotic agents have a risk of cerebrovascular incidents and increased mortality, as well as worsening cognition in elderly people with dementia.

Cholinergic agents may improve neuropsychiatry symptoms in PD, but there is yet no evidence to support their use for VH in PD. Rivastigmine, however, seems to be particularly useful for PD with VH, in that the rapid cognitive decline in this group can be reduced. ■

*"Neuropsychiatry Symptoms in Parkinson's Disease," Movement Disorders, 2009 Nov. 15;24(13): 2175-2186.*

**Dr. Aarsland is a professor of psychiatry at the Norwegian Center for Movement Disorders, Stavanger University Hospital, Stavanger, Norway.**

## SCANS HELP IDENTIFY AND DISTINGUISH DIFFERENT TYPES OF PD AND DEMENTIA

Positron emission tomography (PET) technology is proving a valuable tool in identifying different forms of Parkinson's disease (PD). Chris C. Tang, MD, and his colleagues at the Feinstein Institute for Medical Research, Manhasset, N.Y. report highly accurate identification of different forms of Parkinsonism in their early stages using PET technology.

The scans allowed the researcher to distinguish among idiopathic PD, multiple system atrophy and progressive supranuclear palsy, all PD variations. Early diagnosis is important in selecting and initiating treatment plans and identifying participants for clinical tri-

als. His findings were published in *The Lancet Neurology* earlier this year.

At Washington University, St. Louis, Joel Permuter, MD, a member of APDA's Scientific Advisory Board and a pioneer in the use of PET technology in PD, is investigating its use in distinguishing different types of dementia. With patients who have volunteered for a series of thinking tests, MR and PET brain scans, and have agreed to eventual post mortem brain examination, he is finding new insights into the changes in the brain causing dementia. The study has been entirely funded by APDA's St. Louis Chapter. ■

## Educational Material & Patient Support Resources

APDA is the source of a variety of free educational and patient/care-giver support materials. Most publications listed below can be downloaded from the Web site, [www.apdaparkinson.org](http://www.apdaparkinson.org), publications page. Single copies are available by writing to the national office or calling 800-221-2732, faxing to 718-981-4399, or contacting any APDA Information & Referral Centers throughout the United States.

Free subscription to a monthly e-newsletter and "Tip of the Month" feature is available on APDA's Web site home page. Lotsa Helping Hands, a private, caregiving coordination service that allows family, friends, neighbors and colleagues to create an online community to assist a caregiver with daily tasks can be reached by clicking the "Ease the Burden" button.

APDA's National Resource Center for Rehabilitation provides direct telephone (888-606-1688) and email ([rehab@bu.edu](mailto:rehab@bu.edu)) access to a licensed physical therapist at Boston University's College of Health and Rehabilitation Sciences: Sargent College, to answer questions about exercise, provide information about programs in the caller's area and provide educational materials.



### BOOKLETS

(order by letter)

- A. Parkinson's Disease Handbook
- B. Young Parkinson's Handbook
- C. Be Active
- D. Be Independent
- E. Speaking Effectively
- F. Good Nutrition
- G. Aquatic Exercise for Parkinson's Disease
- H. My Mommy Has PD...But It's Okay!

### SUPPLEMENTS

(order by number)

- 4. Keys to Caregiving
- 5. Hospitalization of a Parkinson's Patient
- 6. The Living Will and Durable Power of Attorney for Health Care

- 7. Parkinson's Disease and Oral Health
- 8. The Family Unit and Parkinson's
- 10. The Challenge of Parkinson's Disease: Adapting to a Nursing Home
- 13. Medical Management of Parkinson's Disease and Medications Approved for Use in the USA
- 16. When Should Parkinson's Disease Patients Go to the Emergency Room?
- 17. Neuro-ophthalmology and PD
- 20. Fatigue in Parkinson's
- 21. Dr. Andrew Weil's Recommendations for Healthy Aging
- 22. Depression and Parkinson's
- 23. Incontinence and Parkinson's
- 24. Employment and Parkinson's
- 25. Constipation and Parkinson's

### FLYERS

- Basic Information about Parkinson's Disease
- National Young Onset Center
- Medications to Be Avoided or Used with Caution in PD
- 34 Helpful Hints to Improve the Quality of Life of People with Parkinson's
- The Importance of Having a Will

### WEB SITES

- [www.apdaparkinson.org](http://www.apdaparkinson.org)
- [www.youngparkinsons.org](http://www.youngparkinsons.org)
- [www.apdawest.org](http://www.apdawest.org)

### DVD

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

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