

NIH ESTABLISHES PROGRAM TO SPEED RESEARCH PROCESS

To speed the process of getting new discoveries from the laboratory to patients, the National Institutes of Health (NIH) has established the National Center for Advancing Translational Sciences (NCATS). The program, with a \$575 million budget, will serve as the nation's hub for catalyzing innovations in translational sciences. Working closely with partners in the regulatory, academic, nonprofit, and private sectors, NCATS will strive to identify and overcome hurdles that slow the development of effective treatment and cures and thus reduce the current 15 to 20 years in the development of new therapies and drugs from basic research to final Federal Drug Administration approval required for patient use.

In announcing the Fiscal Year 2012 spending bill signed by President Barack Obama in December, NIH director Francis S. Collins, MD, PhD said, "Through partnerships that capitalize upon our respective strengths, I believe we can work together to achieve our common goal: speeding the movement of scientific discoveries from the lab to patients."

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APDA-FUNDED RESEARCH LEADS TO ADDITIONAL FINDINGS

Allison Wright Willis, MD, an assistant professor of neurology at Washington University School of Medicine, St. Louis, first published her research findings on the geographic and ethnic variations of Parkinson's disease (PD) in the United States in a 2010 issue of the journal *Neuroepidemiology*. Her pioneering profile of how demographics influence the occurrence of the disease was initially funded by an APDA post-doctoral fellowship, which led to support by the National Institute of Neurological Disorders and Stroke and other government health agencies.

Last month, Dr. Willis and her colleagues at the university (one of nine APDA Centers for Advanced Research) published further findings that demographics and clinical factors appear to be associated with survival in PD, and the presence of dementia is associated with a significant increase in mortality. The report appeared in the *Archives of Neurology*, a Journal of the American Medical Association/Archives journals.

Both reports are based upon a nationwide retrospective cohort study of 138,000 Medicare beneficiaries with PD who were followed from 2002 through 2008.

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FROM THE CHAIRMAN



Joel A. Miele Sr., PE

In one year, three major scientific breakthroughs were realized through the generosity of APDA contributors.

In this issue you will read about Dr. Allison Wright Willis's latest research based upon previous data collected via an APDA 2007 post-doctoral fellowship award.

In the announcement of Dr. Willis's findings, she suggests that Parkinson's patients living in urban high-industrial metal-emission areas had a slightly higher adjusted risk of death, but more work is needed to understand whether environmental exposures can influence the course of PD or survival. That need sparked a memory of Dr. Beate Ritz's APDA-funded research at UCLA's School of Public Health, leading to last summer's announcement that ambient pesticide exposure is as toxic as direct exposure, and the discovery that ziram is a third PD-lined toxic pesticide.

In last spring's newsletter, we reported about the discovery of a drug that stops the progression of PD in mice by Dr. Wendo Zhou, research funded by a 2008 APDA research grant. Dr. Zhou is continuing that study at the University of Colorado School of Medicine with Dr. Curt Freed, another former APDA awardee.

The thread of relevant research weaves through our journey toward understanding and ultimately curing this disease. Many scientists have been quoted as saying that there will be no "Eureka!" moment in finding what causes PD and the cure will evolve through the work in numerous areas. The work being supported in our nine centers for advanced research across the country assures a diversification of studies in genetics; environment; biology; pharmacology; surgical and physiology therapies; radiology; gene research, and psychiatry. It is the work that will one day lead us to the answers of the questions of why people are afflicted

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FROM THE PRESIDENT & CEO



Joel Gerstel

When winter's doldrums set in, I need only look to our network of chapter presidents and Information & Referral Center coordinators and medical directors to brighten things. Knowledge that every day across the country APDA volunteers and healthcare professionals are not only daily maximizing the quality of life for more than a million people and their families, but also providing the support for research

that maintains hope for the future is a source of warmth and comfort.

Being a part of that system makes the dreariest day brighter.

For more than half a century, in good times and bad, the APDA mission has grown. Despite the financial challenges of the past few years, APDA has introduced new services for young onset patients and created the only national rehabilitation resource center. Nine of the country's most prestigious Parkinson's research centers continue to receive annual funding for the studies

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ASK THE DOCTOR By Dr. Michael A. Huber, DDS

Q: I was recently diagnosed with Parkinson's disease (PD) and my mouth feels fine. When should I see my dentist?

A: It is highly recommended that you see your dentist as routinely scheduled and do not hesitate to discuss your diagnosis of PD. By maintaining your oral health, you may be able to prevent or dampen to some degree many of the oral problems associated with PD.

Q: My mouth is dry, what can I do?

A: Dry mouth is a very common complaint and increases one's risk of developing oral infections and discomfort. It is often related to the drugs used to medically manage PD or other medical conditions you may have. In some cases, your physician may be able to change or adjust your medication to reduce dry mouth. However, this is often not the case and strategies to manage dry mouth should be undertaken. There are several simple steps you can accomplish yourself, such as avoiding irritating products like alcohol, tobacco, and spicy or acidic foods. Using sugar-free candies containing xylitol (a non-cariogenic sweetener) helps reduce your oral cavity risks while stimulating salivary flow. Sipping water throughout the day is helpful. Many moisturizing and saliva substitute products are currently available to relieve dry mouth.

These products are usually avail-



Dr. Michael A. Huber

able over-the-counter and may prove beneficial for you. However, there are some proprietary differences among these products and one may work better for you than another. Your dentist will likely place you on a prescription-based fluoride regimen, which is intended to counter the increased cavity risk associated with a dry mouth. An increase in oral discomfort associated with your dry mouth may indicate the presence of a fungal infection for which your dentist may prescribe appropriate therapy.

Q: I am experiencing excessive salivation. What should I do?

A: You are likely suffering from sialorrhea and should discuss the problem with your physician. Up to 78 percent of PD patients may experience the condition, which may manifest as excessive drooling and increased problems with swallowing. A variety of pharmacologic therapies has been proposed to reduce excess salivation, but studies ad-

dressing the issue are limited. Some authorities report that the injection of botulinum toxin into the major salivary glands can reduce excess salivation.

Dr. Huber is Associate Professor, Oral Medicine Subject Expert, Department of Comprehensive Dentistry, Dental School University of Texas Health Science Center, San Antonio. He is the author of APDA's educational supplement "Parkinson's Disease and Oral Health," available by calling 800-223-2732 or downloading from www.apdaparkinson.org.

APDA - FUNDED RESEARCH LEADS TO ADDITIONAL FINDINGS *continued from page 1*

The current study found that dementia was diagnosed in 69.6 percent of the study population with the highest frequency found in Black patients (78.2 percent) followed by Hispanics (73.1 percent), with White and Asian patients having lower but similar rates of 69 and 66.8 percent respectively.

The authors concluded, "Our data highlight the need for prevention of, or treatment for dementia in patients with PD because of its effect on survival."

Dr. Willis's research initially reported PD rates highest in the Midwest and Northern 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 aged 65 and older is affected, and approximately 130,000 people are newly diagnosed each year.

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.

NATIONAL GRANTS WED MATH SCIENCE IN SEARCH OF SLOWING PD SYMPTOMS

A university department of mathematics is not a usual recipient of a grant to find ways to stop the symptoms of Parkinson's disease, but that is exactly what is occurring at the University of Pittsburgh, one of APDA's nine centers for advanced research.

A four-year, \$1.86 million grant from the National Science Foundation and a five-year \$1.2 million grant from the National Institutes of Health are allowing Pitt mathematicians to work with neurobiology researchers using computational models, experiments, and analysis of models and data to study the way that signals are transferred between the basal ganglia (a collection of nuclei found in the brain that helps with motor control) and the thalamus, its downstream target in the brain.

Although scientists can't yet prevent the cell death associated with PD, their study of mathematical patterns could guide the development of less invasive treatments that block the motor symptoms of the disease, according to Jonathan E. Rubin, PhD, a Pitt mathematics professor and member of the school's Center for Basis of Neural Cognition, one of the lead investigators.



“For Parkinson's patients, there are more spurts and pauses in neural activity, and the firing of groups of neurons becomes more coordinated leading to tremor and other symptoms. This firing pattern may be what leads to shaking, rigid muscles, and difficulty in making quick movements.”

Deep brain stimulation (DBS) is a commonly used surgical treatment in which electrodes are implanted in the brain and send out electrical impulses to control symptoms after standard drug therapies no longer work.

The Pitt research is attempting to understand the neuronal activity patterns so as to improve the DBS procedure, making it more individualized and efficient.

UNITY WALK SET FOR APRIL 28

The 18th annual Unity Walk will take place in New York City's Central Park, Sat. April 28. The 1.4-mile walk is the country's largest grassroots event for Parkinson's disease with 100 percent of donations going to research. In addition to the walk, participants have the opportunity

to talk to a movement disorder specialist, neurosurgeon, physical therapist and other PD specialist at an “Ask the Doctor” booth, learn about new therapies and clinical trials and how to become a PD advocate, take part in a raffle, and meet and be inspired by other members of

the Parkinson's community.

Last year's event raised more than \$1.5 million for research.

Information is available by calling 866-PUW-WALK (866-789-9255) or online www.unitywalk.org.

PARTNERS IN HELPING PEOPLE WITH PD



APDA's San Antonio Information & Referral Center coordinator Dianne Johnson, RN, (left) joins Dr. Melinda Rodriguez, (center), and Faye Schoenrock, (right) of Access Quality Therapy Services showing off the US Commerce Association Best of San Antonio Award presented for their Parkinson's Outreach Program.

FROM THE CHAIRMAN *continued from page 2*

with PD, how can we predict and avoid it, and how can we cure it when it occurs.

And until then, our support system and educational programs of Information & Referral Centers and support groups remain the largest in the country offering PD patients and their caregivers the means to live as full a lifestyle as possible. And, our supporters can feel confident and content that their contributions are working to achieve our common goal.

FROM THE PRESIDENT & CEO *continued from page 2*

from which the cause and cure will eventually be found.

And to expand the wonder is the fact that no government or public dollars pay to sustain this huge network. It is primarily the contributions of individuals paired with support from foundations



APDA HAS "OPTIMISM" AND IT'S CONTAGIOUS

APDA has launched a new national campaign to increase awareness of Parkinson's disease across the country and to raise money for education, support services, patient and caregiver programs, and to find the cure.

The Optimism campaign provides unlimited ways to get involved to help "Ease the Burden – Find the Cure." On the website www.optimism4parkinsons.org, young and old can find events in which they can participate or become involved by creating customized event pages for memorials, honoring someone, special events, weddings, anniversaries and birthdays, and personal requests. The site also includes a starter kit with everything needed to launch any kind of an event – mail and e-mail templates to announce the event and invite participation, a t-shirt design, event signage and banner templates, event guidelines and checklists, and tips for hosting an event.

Optimism can achieve anything and APDA's Optimism campaign is the first step.

and companies that allow us to maintain the largest grassroots organization for America's people with PD.

So, while we look forward to the holidays of spring, of warmth and rebirth, at APDA every day is Thanksgiving.

APPLYING FOR DISABILITY: STEPS FOR SUCCESS By Julie Sacks

In our current economy, the possibility of unemployment is a reality for many. For someone with Parkinson's disease, concerns about job loss often loom large. Learning all you can about how the Social Security Administration (SSA) determines disability can be very helpful. Generally, those who clearly understand SSA's Five Step Sequential Evaluation Process submit more complete and convincing applications that have a greater likelihood of approval.

Five Step Sequential Evaluation Process

1. Are you working? If not or if earning less than an average of \$1,010 a month, go to Step 2.

2. Is your condition "severe?" If "severe" enough to "interfere with basic work-related activities," go to Step 3. Of course, assessing severity is subjective leaving many applicants having to prove disability to SSA.

3. Is your condition found in the list of disabling conditions? Parkinsonian Syndrome, not Parkinson's disease, is on the SSA list of medical conditions. Only when SSA considers your condition to be "of equal severity to a medical condition that is on the list" will it find that you are disabled. If

it is not, you go to Step 4.

4. Can you do the work you did previously? If your condition is not as severe as a medical condition on the list, SSA has to determine if it interferes with your ability to do the work you did previously. If they determine it does, you go to Step 5.

5. Can you do any other type of work? SSA determines if you are able to adjust to other work taking into consideration your age, education, past work experience, and transferable skills.

Keep in mind that a diagnosis of Parkinson's in and of itself is not considered disabling. This can be frustrating when you are ready to apply, but having PD excluded from the automatically disabled list of conditions does allow people with the disease to continue working, sometimes for many years, depending on the job. When you are ready to apply, you can learn more about these steps and the information SSA is seeking at each point in the process by visiting www.ssa.gov or by visiting the APDA National Young Onset Center Website at www.youngparkinsons.org.

Ms. Sacks is the director of APDA's National Young Onset Center.

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A recommendation to create a new center dedicated to advancing translational science by the NIH Scientific Management Review Board in December of 2010 was followed by a year of intensive feedback and expert insight from all sectors of translational science through advisory meetings and extensive public consultation resulted in NCATS' formation.

"I am deeply grateful for the expertise and insight provided by the many researchers, industry executives, patients, voluntary organizations and NIH staff that help NIH evaluate NCATS' purpose and crystallize its vision," said Dr. Collins.

Additional information about the impetus and development of NCATS is available at www.nih.gov/about/director/ncats.

APDA DIRECTOR IN TOP PROFESSIONAL POST

Robert Browne, DC, a member of APDA's Board of Directors, has been elected president of the New York Chiropractic Council. Dr. Browne is also the recipient of the Council's 2011 Distinguished Service Award.

LET THE PATIENT BEWARE By Stewart A. Factor, D.O.

The unfortunate undisputable truth about Parkinson's disease (PD) is that there is currently no cure. There are a number of treatments to hold the symptoms at bay, but nothing that stops it from progressing. Because of this, patients and their loved ones can be victimized in ways beyond the misfortune of the devastating disease.

A PD patient I knew well for 10 years who was asked to my office by his son, who asked that I speak to a physician. The "doctor," however was not a physician, but a scam artist selling naturopathic remedies (I learned about him later from a variety of websites). He made incredibly outrageous claims without ever laying eyes on the patient, including one that "Parkinson's disease is simple" and that he could cure it in "three weeks" with his remedies. He denigrated university professors claiming he had cured people previously diagnosed with Alzheimer's disease, which he said was generally a nutritional deficiency.

The patient's son had purchased nearly \$700 of products, which were nothing more than vitamins and minerals that could be purchased elsewhere for a fraction of the cost. When the son reviewed the list with the man, he was told he needed to purchase more.

There is, unfortunately, no shortage of fraudulent treatments made available to the public. Among the "cures" are:

- Easily available over-the-counter vitamins and minerals in the guise of scientific-sounding names,

- Expensive infusion therapies with glutathione, chelators, growth factors, amino acid cocktails and various forms of nutrients,
- Bogus stem cell therapies, whereby stem cells are removed from fatty tissue and given in intravenous infusions or injections on the lower spine or back of the neck. (The procedure has no proven benefit and the FDA has not approved it.)

The most obvious reason people fall for these scams is a sense of desperation in knowing one has an incurable, progressive disabling disease.

Second, well-intentioned family members indiscriminately suggest websites, publication ads and articles promoting various treatments and cures, and popular media reports of news-breaking "medical discoveries."

Current medicine is by no means perfect, but physicians provide FDA-approved treatments that have been studied in a systematic scientific manner with results published in peer-reviewed periodicals. Naturopathic organizations are not held to the same scrutiny and use testimonials from individuals who may be paid by the company.

Alternative therapies for the most part are considered medically harmless, and a patient having the time, money and desire will decide independently whether to use them.

But are they harmless? Is it harmless to scam chronically ill patients and drain them of resources that

could be used to hire a private duty physical therapist to sustain or regain strength and independence?

When these treatments fail, patients usually do not come forward because of their embarrassment at being duped. Patients should feel comfortable to ask their physicians when faced with outrageous claims about alternative therapies until these therapies are subject to the same scrutiny level as FDA-approved drug therapies.

Dr. Factor is a professor of neurology at Emory University School of Medicine, Atlanta, a movement disorder neurologist, and a clinical research investigator.

NINDS CAUTIONS AGAINST ONLINE MEDICAL ADVICE

The National Institute of Neurological Disorders and Stroke (NINDS) recently cautioned viewers of YouTube videos that many inaccurately depict Parkinson's disease and other movement disorders.

In a letter to the New England Journal of Medicine, NINDS cited research by neurologists at University College London showing that a majority of the videos showing abnormal movement originated from a psychological condition or mental state rather than a disease such as PD. More than half of the videos viewed contained advice about specific therapies to treat the disorder.

NINDS senior investigator Mark Hallett said, "There is a great deal of good information on the Internet, but one has to be careful."

EDUCATIONAL MATERIAL AND PATIENTSUPPORT RESOURCES

Information on Parkinson's Disease

APDA is the source of many free educational and patient/caregiver support materials. Most publications listed below can be downloaded from the website, www.apdaparkinson.org, publications page. Single copies are available by writing to the national office or calling 800-223-2732, faxing to 718-981-4399, or contacting any of the APDA I&R Centers.

Free subscription to a monthly e-newsletter and "Tip of the Month" feature are available on APDA's website 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 Young Onset Center is located at Central DuPage Hospital, 25 North Winfield Road, Winfield, IL. www.youngparkinsons.org, 887-223-3801, info@youngparkinsons.org.

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



BOOKLETS

(order by letter)

- A.** Parkinson's Disease Handbook
- B.** Young Parkinson's Handbook
- C.** Be Active
- D.** Speaking Effectively
- E.** Good Nutrition
- F.** Aquatic Exercise for Parkinson's Disease
- G.** 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
- 9.** Maintaining Independence
- 10.** The Challenge of Parkinson's

- 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
- 22.** Depression and Parkinson's
- 23.** Incontinence and Parkinson's
- 24.** Employment and Parkinson's
- 25.** Constipation and Parkinson's
- 26.** What is Dysphagia?

OTHER PUBLICATIONS

- Basic Information about Parkinson's Disease
- National Young Onset Center
- How to Start a Support Group
- 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

WEBSITES

- www.apdaparkinson.org
- www.youngparkinsons.org

DVD

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

AVAILABLE for DOWNLOAD at www.apdaparkinson.org

- Be Independent: Equipment and Suggestions for Daily Living
- Dr. Andrew Weil's Recommendations for Healthy Aging (Supplement 21)