



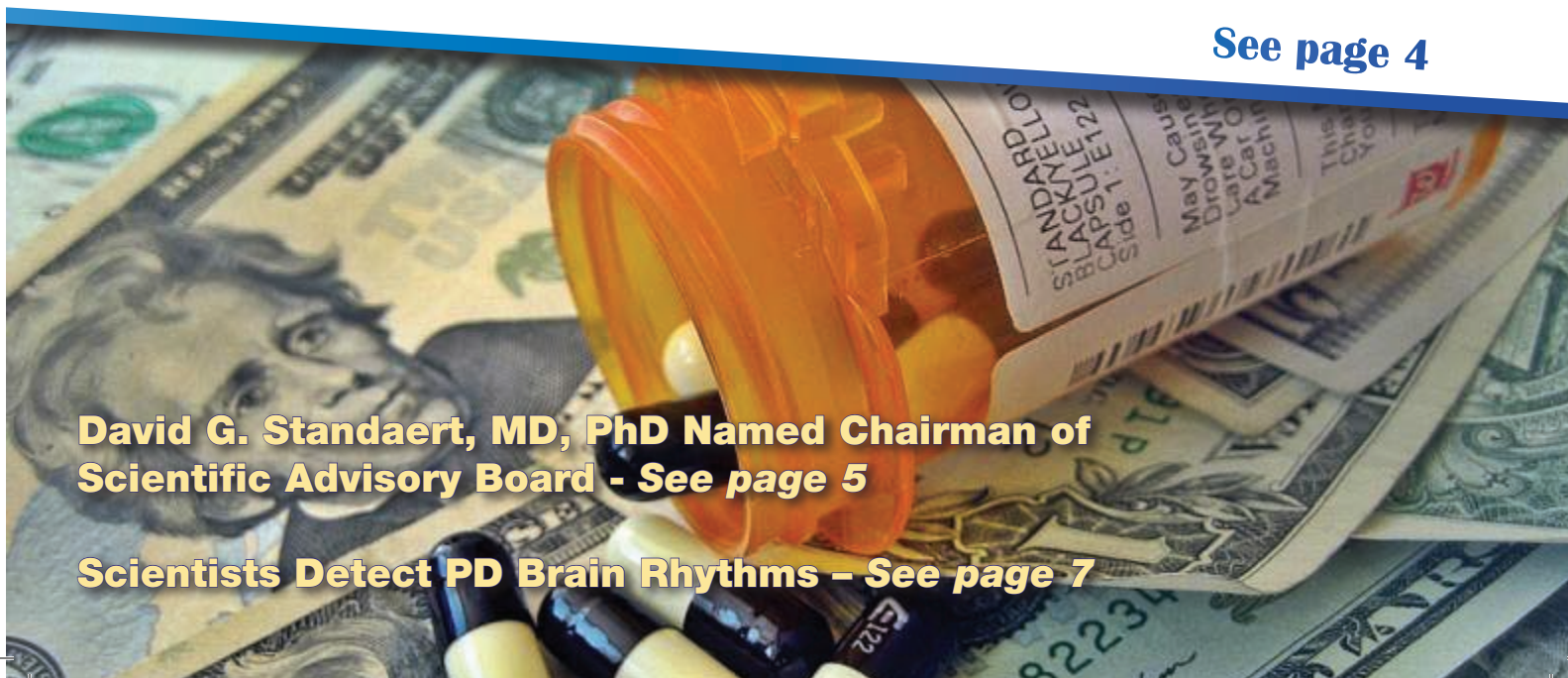
AMERICAN PARKINSON DISEASE ASSOCIATION

SPRING
ISSUE 2013



Parkinson's disease currently costs the U.S. economy at least \$14.4 billion annually, and is expected to double in the next 25 years.

See page 4



**David G. Standaert, MD, PhD Named Chairman of
Scientific Advisory Board - See page 5**

Scientists Detect PD Brain Rhythms - See page 7

FROM LESLIE A. CHAMBERS, PRESIDENT & CEO



I was honored to be invited to the White House this month to represent APDA at President Obama's unveiling of the Brain Initiative – “a new research initiative designed to revolutionize our understanding of the human brain. Launched with approximately \$100 million in the President's Fiscal Year 2014 Budget, the BRAIN (*Brain Research through Advancing Innovative Neurotechnologies*) Initiative ultimately aims to help researchers find new ways to treat, cure, and even prevent brain disorders, such as Alzheimer's disease, epilepsy, and traumatic brain injury. ”The President also referenced Parkinson's in his comments during the briefing.

The President further “called on companies, research universities, foundations, and philanthropists to join with him in identifying and pursuing this initiative as part of his administration's “Grand Challenges of the 21st Century.”

It was a great opportunity for APDA and the Parkinson's community, and strong evidence that our collective efforts can make a difference.

On the note of collective efforts, our annual Optimism walk-a-thon campaign is going into full

gear as the weather warms across the country. In the past, all proceeds of these walks were restricted to scientific research, but this year we are expanding the beneficiary base to include patient and caregiver programs in local communities. This means that each step is providing both help for his/her neighbor now, and hope through scientific research for a cure for all 1.5 million people with PD.

Join a walk in your area. All are listed on our website, www.apdaparkinson.org, or call 800-223-2732 for the walk date and place in your locale.



Leslie A. Chambers, President & CEO, and the National Office staff literally get behind APDA's Optimism campaign that raises hundreds of thousands of dollars for scientific research and patient/caregiver educational and support programs.

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Hopeful PD Drug Fails In Phase 2 Clinical Trial

Cogane, a drug designed to promote the release of GDNF and BDNF in the brain, proved to have no beneficial effects on patients' symptoms in a phase 2 clinical study. Scientists were hopeful that the two proteins, which are believed to have the potential to restore life to some brain cells, could be effective in slowing the progress of PD and other degenerative diseases.

Tim Sharpington, chief executive of Phytopharm, the British biotech company that manufactured the drug, said that Cogane had demonstrated encouraging efficacy in pre-clinical models but failed to show any benefit over placebos in clinical trials.

GDNF and BDNF have shown potential in PD, but until Cogane, which is taken by mouth, administering them was limited to invasive surgical procedures.

SPRING 2013

Issue No. 102 © 2013

Published quarterly by the American Parkinson Disease Association, Inc.
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ASK THE DOCTOR

By J. Timothy Greenamyre, MD, PhD



Dr. J. Timothy Greenamyre

Q: *I have read that there is a deficiency of glutathione in Parkinson's disease. Several people with Parkinson's that I know are going to practitioners who give them intravenous glutathione treatments. Is this something that I should start doing?*

A: This is a very interesting and important question. First, it is true that there is a loss of glutathione in the brains of people with PD, and this loss occurs very early – probably even before there are symptoms. The decrease in glutathione is important because this chemical acts as an antioxidant to help protect neurons from oxidative stress. As the neurons (nerve cells) become depleted of glutathione, they are less able to resist the everyday stresses that are part of being a brain cell. Furthermore, we know that if we can boost the glutathione levels of dopamine neurons in a dish, they become more resistant to toxins and genetic mutations that cause PD.

So, why aren't we giving glutathione to everyone with PD? Unfortunately, it's just not that simple. If we were to give glutathione orally in pill form, it would not be absorbed intact and would do no good. For this reason, some practitioners are giving glutathione intravenously. However, even when given in this way, it's not clear how much – if any – of the glutathione gets into the brain. This is because the brain is protected by the 'blood-brain-barrier,' which prevents many chemicals and drugs from moving from the bloodstream into the brain tissue. It has not been shown that such treatments can boost brain levels of glutathione.

More importantly, a randomized, double-blind, clinical trial of intravenous glutathione given every Monday, Wednesday and Friday for four weeks failed to demonstrate any benefit. So, despite the presence of videos on the Internet showing apparently miraculous results, there is no rigorous scientific evidence that this approach is helpful in any way. What's more, there is at least one report that intravenous glutathione may cause liver damage. At this point, then, I cannot recommend intravenous glutathione for the treatment of PD.

Q: *What about chelation therapy? I have heard that it has helped a lot of people with Parkinson's disease?*



A: Chelation therapy refers to the administration of chelating agents (chemicals) in order to remove certain heavy metals (for example: lead, mercury, arsenic or iron) from the body. Although some scientists think there are abnormalities in the way neurons handle iron in PD, this is poorly understood – and the rationale for trying chelation therapy is not strong. There have been no randomized clinical trials of chelation therapy for PD, so there is no good evidence that it is useful.

Is it safe? Although PD is not an approved reason for using chelation therapy, this treatment is generally relatively safe if performed appropriately. On the other hand when it is not performed appropriately, it has been associated with numerous deaths – and there is also evidence that it may lead to permanent cognitive impairments. I cannot recommend chelation therapy for people with PD.

Dr. Greenamyre is Professor & Vice-Chair of Neurology Director, Pittsburgh Institute for Neurodegenerative Diseases at the University of Pittsburgh

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.

PD's Cost - \$14.4 Billion a Year and Growing



From combined reports

The physical and psychological burden that Parkinson's disease imposes upon a patient and the family cannot be quantified, but two recent studies published in the journal *Movement Disorders* show the economic impact: \$14.4 billion in medical and indirect costs, or \$22,800 per patient.

The studies are "The Current and Projected Economic Burden of Parkinson's Disease in the United States" (Kowal, Dall, Chakrabarti, Storm, and Jain) and "An Economic Model of Parkinson's Disease: Implication for Slowing Progress in the United States" (Johnson, Diener, Kaltenboeck, Birnbaum, and Siderowf).

Some of the key findings in the first study are:

- \$ The disease's current annual cost to the economy is at least \$14.4 billion.
- \$ Personal medical expenses for people with PD are \$22,800 — \$12,800 more than for someone without the disease. The American PD population accounted for 1.9 million hospital inpatient days in 2010, 73 percent more than the population without the disease. In the same year, there were 1.26 million doctors' office visits, 57,000 outpatient visits, 31,000 emergency room visits, 24,000 home health aide days and 26,000 hospice days.
- \$ Nursing home expenses account for almost 60 percent (\$5 billion) of the excess medical costs.
- \$ Indirect costs such as missed work or job loss, long-distance travel for specialized medical care, home modifications, and adult day care cost more than \$6 billion each year.
- \$ The prevalence of PD is expected to double in the next 25 years.

Cost reduction in second study

According to the second study, if PD progression were slowed by half, there would be a 35 percent reduction in excess costs, representing a dramatic reduction in the cost of care spread over a longer expected survival.

Amy Comstock Rick, CEO of the Parkinson's Action Network, the Washington DC-based advocacy organization representing all the major PD national organizations, noted, "The authors of 'The Current and Projected Economic Burden of Parkinson's Disease in the United States' acknowledge their findings are conservative estimates due to limits in available data... In reality, the prevalence and economic-burden numbers are even higher and will grow exponentially over the next few decades. The silver tsunami of aging baby boomers will bring not just a dramatic increase in Parkinson's diagnoses, but also significantly higher costs burdens to families that are already stretched too thin. Funding for Parkinson's disease and all biomedical research must be a considered a priority..., and cannot be cut in any way, shape, or form."



David G. Standaert, MD, PhD to Chair APDA's Scientific Advisory Board

David G. Standaert, MD, PhD, the John N. Whitaker Professor and Chair of Neurology at the University of Alabama – Birmingham (UAB), has been named chairman of APDA's Scientific Advisory Board (SAB). Dr. Standaert succeeds G. Frederick Wooten MD, and is the board's fourth chairman.

Dr. Standaert, who also heads UAB's Division of Movement Disorders and Center for Neurodegeneration and Experimental Therapeutics, joined the SAB in 2002.

"We are just delighted that Dr. Standaert has accepted the SAB chairmanship," said Leslie A. Chambers, President & CEO in announcing the appointment. "He is widely recognized and respected in the national Parkinson's disease community as a dedicated and talented scientist and clinician."

Perhaps it was partially genetics (his dad was the chair of the Georgetown Department of Pharmacology) and partially subliminal (his grandfather had PD) that led him to Harvard University from which he graduated magna cum laude in biochemistry, and Washington University School of Medicine, St. Louis, where he earned a dual MD, PhD degree. He began working in his father's laboratory at age 14 and had published a paper in a scientific journal by 17.

His post-graduate studies were completed at Jewish Hospital, St. Louis; the University of Pennsylvania and Harvard Medical School Massachusetts General Hospital, where under the tutelage of former APDA George C. Cotzias, MD Fellowship recipients Drs. John Growdon and Stephen Fink, applied for and was named a fellowship recipient in 1996. He has called that event as, "one of the most important events in establishing my long-term commitment of Parkinson's disease research. It was a crucial moment in my career."

Dr. Standaert reports that his laboratory is interested in the pharmacology and neurochemistry of the basal ganglia, and the mechanisms of Parkinson's

disease and other conditions which produce abnormalities of movement. "Our experimental approaches combine classic neuroanatomical methods with modern techniques of molecular and cell biology, using in situ hybridization, immunohistochemistry, laser capture microdissection, gene array profiling, animal models of disease, and in vitro systems," he says.



Dr. Standaert, right, explains a slide of Parkinson's model brain tissue to support group member Ken Carter.

Other SAB members are James Bennett, Jr., MD, PhD, Virginia Commonwealth University; Marie-Francoise Chesselet, MD, PhD, UCLA School of Medicine; Mahlong DeLong, MD, Emory University School of Medicine; Dennis Dickson, MD., Mayo Clinic College of Medicine; Un Jung Kang, MD, University of Chicago; Laura Marsh, MD, Michael E. DeBakey VA Medical Center; Erwin Montgomery Jr., MD, UAB; Mary Maral Mouradian, MD., UMDNJ-Robert Wood Johnson Medical School; Richard Myers, PhD, Boston University School of Medicine; Joel Perlmutter, MD, Washington University; Marie Saint-Hilarire, MD, Boston University School of Medicine; Evan Yale Snyder MD, PhD, Burnham Institute for Regenerative Medicine; and Ray Watts, MD, UAB.

Air Travel is Easier With TSA Information



With air travel about to begin its heaviest season, the Transportation Security Administration (TSA) has established the TSA Cares Help Line to assist passengers with disabilities and medical conditions as an additional, dedicated resource specifically for passengers with disabilities, medical conditions or other circumstances, or their loved ones, who want to prepare for the screening process prior to flying.

Travelers may call 855-787-2227, Monday through Friday 8 a.m. – 11 p.m. EDS and weekends and holidays 9 a.m. – 8 p.m. EDS. Travelers who are deaf or hard of hearing can use a relay service to contact TSA Cares or may e-mail TSA-ContactCenter@dhs.gov with questions about screening policies, procedures and what to expect at the security checkpoint. TSA



recommends that passengers call approximately 72 hours before traveling so that TSA Cares has the opportunity to coordinate checkpoint support with a TSA customer service manager at the airport when necessary.

A representative will provide assistance, either with information about screening that is relevant to the passenger's specific disability or medical condition, or the passenger may be referred to disability experts at TSA.

Additional travel security information, including prohibited items and downloadable brochures, is available at www.tsa.gov.

Sharing: Worry's Perfect Antidote

By Julie Sacks



Do you worry? About the kids, the house, the bills? Worry, like guilt, is often referred to as a useless emotion.

That doesn't mean it's easy to stop worrying. It's just that worry by itself doesn't change anything. Whether you're a person with Parkinson's disease, a primary caregiver, a family member or friend of someone with the disease, you know what it is to worry.

To some extent, our society values worry, "She's such a good friend, worrying about him all the time." But think about the possibilities that exist when worry is turned into action. "She was so worried about his going to the doctor's office alone, she took off work and went with him." Of course, there are many circumstances in which there is no such easily identifiable plan of action.

Those are the very situations in which worry can

take the driver's seat and make you feel like a passenger being dragged along. If (or more likely when) you find yourself in a position like this, remember you have options. Sharing your worries with another person (your doctor, friend, partner or spouse) can take away some of the fear that tends to accompany it.

Taking advantage of the resources available to you is another way to decrease the amount of time you spend worrying. The APDA National Young Onset Center maintains a Resource Guide that can help people of all ages manage PD-related challenges. Find the category you're worrying about, and contact a few of the organizations listed. If you do not have Internet access, to get this information by phone, call us at 877.223.3801.

Action can sometimes be the perfect antidote for worry.

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

Parkinson's Brain Rhythms Detected

By Susan F. Gulas, RN

A team of scientists and clinicians at the University of California, San Francisco (UCSF) has discovered how to detect abnormal brain rhythms associated with Parkinson's by implanting electrodes within the brains of people with the disease. Their work may lead to developing the next generation of brain-stimulation devices to alleviate symptoms for people with the disease.

Described in the journal *Proceedings of the National Academy of Science*, the work sheds light on how Parkinson's disease affects the brain and is the first time anyone has been able to measure a quantitative signal from the disease within the cerebral cortex, the outermost layers of the brain that helps govern memory, physical movement and consciousness.

"Normally the individual cells of the brain are functioning independently much of the time, working together only for specific tasks," said neurosurgeon Philip Starr, MD, PhD, a professor of neurological surgery at UCSF, and a member of the VA Parkinson's Disease Research, Education and Clinical Centers (PADRECC) with the San Francisco Veterans Administration Medical Center, and senior author of the paper. But in Parkinson's disease, he said, many brain cells display "excessive synchronization," firing together inappropriately most of the time.

"They are locked into playing the same note as everyone else without exploring their own music," Starr explained. This excessive synchronization leads to movement problems and other symptoms characteristic of the disease.

The new work also shows how deep brain stimulation (DBS), which electrifies regions deeper in the brain, below the cortex, can affect the cortex itself. This discovery may change how DBS is used to treat Parkinson's and other neurologically based movement disorders, and it may help refine the technique for other types of treatment.

Ms. Gulas is the coordinator of APDA's Veteran's Information & Referral Center in Reno, Nev.

Veterans Update

VA Expands Dates of Agent Orange Exposure in Korea from 1968-1969 to 1968-1971

Veterans who served along the demilitarized zone (DMZ) in Korea during the Vietnam War now have an easier path to health care and benefits. The Department of Veterans Affairs (VA) has expanded the dates when illnesses associated with exposure to Agent Orange can be presumed related to their military service.

Previously, VA recognized exposure for service between April 1968 and July 1969. VA now presumes exposure for service between April 1, 1968, and Aug. 31, 1971, if a Veteran served in a unit determined by VA and Department of Defense to have operated in an area of the DMZ where Agent Orange or other herbicides were applied. The expanded dates took effect on Feb. 24, 2011 (see www.publichealth.va.gov/exposures/agentorange/korea.asp).

This presumption simplifies and speeds the application process for Veterans of the Korean DMZ. VA says it encourages Veterans who believe they have health problems related to Agent Orange to submit their application for VA health care and disability compensation benefits.

To apply for health care benefits online go to www.1010ez.med.va.gov/sec/vha/1010ez, or contact the nearest VA health care facility at 877-222-VETS (8387). To file a claim for disability benefits, apply online at www.ebenefits.va.gov, or contact the nearest VA regional office at 800-827-1000.

Website for Women Veterans: The Department of Veterans Affairs now has a website devoted strictly to women veterans. Visitors can go to www.womenshealth.va.gov to find tools and resources for and about women veterans, including statistics, tips on wellness and healthy living, recent news, and links to publications, products, VA's Health awareness and Culture Change campaigns, and links to VA's Facebook and Twitter pages. Also on the site is the recently developed Women Veterans Outreach Toolkit, which includes fact sheets on VA care and benefits, answers to frequently asked questions, brochures on VA services and health-care awareness materials.

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 subscriptions 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 Rd. 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 e-mail (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

- 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?
- 27.** Cognitive Changes in PD

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)
- The Challenge of Parkinson's Disease: Adapting to a Nursing Home