APDA
TO EASE THE BURDEN TO FIND THE CURE

AMERICAN PARKINSON DISEASE ASSOCIATION

WINTER 2014 ISSUE

Officers, New Directors Elected At APDA's Annual Meeting

Fred Greene, center, elected chairman at APDA's annual meeting in January, poses with President & CEO Leslie A. Chambers, left, and newly elected directors Athol Cochrane, second from left, and David G. Standaert, MD, PhD, right, and national treasurer Elena Imperato, second from right.

See details on page 2

FDA Orders Genetic Testing Firm To Discontinue Marketing Plan

By G. Frederick Wooten Jr., MD

In November 2013, the Federal Drug Administration (FDA) ordered 23andMe, a company that offers genetic testing to determine genetic predisposition to a wide variety of conditions, to stop marketing its genetics testing service.

The FDA took this step because it held that the 23andMe DNA testing violates the Federal Food, Drug and Cosmetic Act, which directs that devices used "in the diagnosis, cure, mitigation, treatment or prevention of disease in man" require FDA approval. No such approval was obtained by 23andMe.

Basically, the FDA has expressed concerns about the company's ability to produce adequate scientific evidence that the 23andMe tests provide accurate genetic results; further, the FDA expressed concerns that unsubstantiated genetic information derived from 23andMe tests could result in unnecessary or even dangerous decisions regarding health.

The action of the FDA was taken without any public evidence that the 23andMe tests are not accurate. Rather, the company has not provided evidence to

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FRAN: A Love Story PD Can Not Alter

Francine Justa was one of the most respected and charismatic leaders of New York City's affordable housing movement in the 1980s and a pioneer of many affordable housing issues until Parkinson's disease forced her retirement in 2003.

Among her achievements were raising $9 million for 10 community-based Neighborhood Housing Services (NHS) programs, increasing annual investments for low- and moderate-income housing from $800,000 to more than $200 million, overseeing gut-rehabilitation of more than 300 homes and mixed-use buildings in low- to moderate-income neighborhoods throughout the city, and founding and leading the Fifth Avenue Committee, which provided services and capital to a resource-poor neighborhood.

Her husband Morris (Moe) Kornbluth is a retired computer programmer who has been her caregiver for more than 10 years and shares that at first he couldn't comprehend the changes that were

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Moe and Fran enjoying a day by the Brooklyn waterfront with daughter Sarah and dog Carroll in the 80s.

MEET APDA CHAIRMAN *Fred Greene*

APDA's ninth chairman is Fred Greene, a retired corporate executive and journalist and longtime volunteer for people with Parkinson's disease. His association with APDA began in 1992, a year after his first wife, Idalee, passed away from the effects of PD, and he founded its North Texas Chapter. He was elected to the national board of directors and five years later to the executive committee. He has served on numerous committees and was elected first vice chairman in 2010. He became chairman to complete the term of Joel A. Miele Sr., who died in May 2013, and was elected chairman at last month's annual meeting.

Mr. Greene had the positions of vice president for public relations for Zale Corp., a leading North American fine jewelry retailer, and director of corporate communications for the Dallas-based conglomerate Hydrometals, Inc. until starting Greene-Webb Associates, a public affairs/marketing/communications company with Thom Webb in 1970. He was the philatelic editor and columnist for the Dallas Morning News for 25 years. His journalism credentials include southwest editor for McGraw-Hill Publications and editor and editorial writer for Harte-Hanks Newspapers in Big Spring and Corpus Christi, Texas.

A native of New Rochelle, N.Y., Mr. Greene earned a bachelor's degree in journalism from the University of Missouri and served in the U.S. Army from 1943 to 1946. He lives in Dallas with his wife, Libby.

IN OTHER ELECTION RESULTS ...

Rhode Island-based financial planner Athol Cochrane was elected to the board of directors. He has headed Wealth Solutions, LLC, a Newport financial services company for 25 years, and has served as the president of APDA's Rhode Island Chapter for more than 13 years. He is also president of the St. John's College Foundation, Johannesburg, South Africa, and a member of the board of the National Tennis Club.

David G. Standaert, MD, PhD, chairman of neurology at the University of Alabama at Birmingham and chairman of APDA's Scientific Advisory Board, has a long-standing relationship with APDA beginning in 1995 when after graduating from Harvard University and Washington University School of Medicine and serving three postdoctoral rotations, he was awarded a George C. Cotzias Fellowship. Dr. Standaert also directs APDA's University of Alabama at Birmingham Center for Advanced Research.

Elena Imperato, who was elected treasurer, has been a member of the board of directors since 1999 and was elected to the executive committee in 2011. She currently manages the Staten Island, N.Y. condominium, Fairview Towers.

Re-elected to the board of directors were Patrick McDermott, John Marangos, Elizabeth Braun, Vincent Gattullo and Thomas Penett.

APDA Launches Website Tribute Page For In Memorial and In Honor Gifts

APDA has launched a new Tribute Page on its website www.apdaparkinson.org that will allow donors to pay tribute to or remember a loved one with a gift of $100 or more. Tribute donations further APDA's mission by funding support and education for people living with Parkinson's disease and scientific research to find the cure. The electronic Tribute Page is only one of APDA's many green initiatives to minimize paper and print costs and ensure that the maximum percentage of donations goes directly to *Ease the Burden – Find the Cure*. Tribute names will remain on the website for three months after posting.

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ASK THE DOCTOR *By Marie Saint Hilaire, MD*

Dr. Marie Saint Hilaire

Q. Could Parkinson's be caused by a blow to the head as a child?

A. Currently there is no definitive cause of Parkinson's disease, so we cannot say that the head injury caused the PD. Individuals who have had a head injury with a loss of consciousness have a greater risk of developing PD than a person who has not. There are many questions to be answered, however, such as why don't all people with a head injury develop Parkinson's? Scientists are working hard to determine what the risk factors are and, we hope, the cause of PD.

Q. I'm 64 years old with PD and getting ready to pursue DBS, but I need to know if it helps with psychosis and cognitive problems? I can live with muscle rigidity, tremor, fatigue, etc.

A. DBS does not directly improve cognitive problems and psychosis; however, some individuals have cognitive problems and psychosis caused by their Parkinson's medications. If DBS improves motor symptoms enough so that less medication is required, then a person may have an improvement in behavior and cognition after the decrease in medication. Other individuals have cognitive problems because of their Parkinson's disease; DBS will not improve these symptoms. Careful screening of general physical and mental health is important before surgery to determine if a person is a good candidate. It is important to have this discussion with your neurologist and DBS team.

Q. Is there any information about the use of medical marijuana as a benefit for Parkinson's symptoms?

A. There has been increased interest in this as states are legislating the use of marijuana for medicinal purposes. Unfortunately, there have not been adequate controlled studies to look at the benefits as well as potential adverse effects of using marijuana with a PD diagnosis. When physicians prescribe a treatment, it is important to know what benefits their patients may expect, and it is equally important to know what side effects may occur. PD symptoms are complex, with motor signs (tremor, muscle stiffness, slowness of movement) as well as non-motor signs (depression, anxiety, sleep disturbance, difficulty with organization). Medications used to treat one symptom may worsen another. For example, if a drug is used to decrease anxiety, might it impair function while a person is driving? Controlled studies are important to make decisions on risk and benefits. Much more work needs to be done in this area.

Q. What articles and/or advice are there on how the weather temps are affecting those of us with Parkinson's?

A. It is known that temperature change does affect individuals with Parkinson's. The autonomic nervous system, which controls body temperature as well as blood pressure and other bodily functions , is affected in Parkinson's. Some individuals have a problem with increased sweating at normal temperatures and this can be more obvious in heat and humidity. Individuals commonly share that extreme temperatures too cold or too warm affect how they feel. The best advice is to avoid becoming too warm or too cold. It is important to stay hydrated and get plenty of rest. Exercise is important and should be done at mildly cool room temperature. Avoid over activity in the heat.

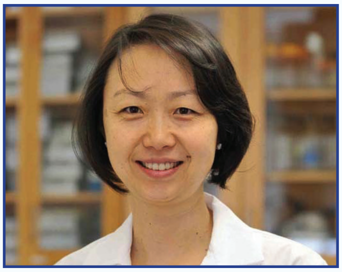
Q. What do you know about a clinic in Mexico that uses fetal stem cells to treat PD?

A. There are no studies proving the benefit of stem cell therapy in Parkinson's disease anywhere. We are not familiar with this program but know that there is no evidence that this works.

Dr. Saint Hilaire is Director of the Parkinson's Disease & Movement Disorder Center at Boston University School of Medicine, and member of APDA's Scientific Advisory Board.

2013-2014 Research Grants Awarded To Scientists

Scientific research support is one half of APDA's mission to Ease the Burden – Find the Cure. Among the groundbreaking research it has funded has been Dr. George Cotzias's discovery that high-dose oral levodopa effectively controls PD symptoms, which more than 40 years later remains the standard treatment, and Dr. Roger Duvoisin's Contorsi family research that established the role of heredity in PD. Today, through the guidance of its Scientific Advisory Board (SAB), a panel of leading experts in all areas of PD, APDA continues to support research, including the pioneering studies establishing the benefits of exercise and the effect of environmental toxins. In May, under the chairmanship of David G. Standaert, MD, PhD, the SAB awarded 11 grants including seven one-year $50,000 research grants to the scientists shown here.

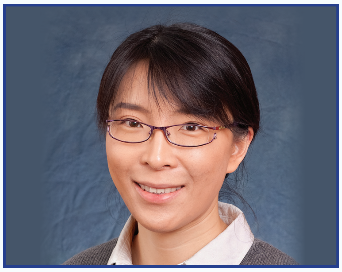


Ming Guo, MD, PhD
UCLA David Geffen School of Medicine

"Identification and Characterization of a Suppressor of the PINK1/Parkin Pathway in Drosophila and Mammalian Cells"

Sheng-Han Kuo, MD
Columbia University

"The Role of Glucocerebrosidase and Chaperone-medicated Autophagy in Parkinson's Disease"



Xin Qi, PhD
Case Western University School of Medicine

"Protection of Mitochondrial Function in Neurons from Patients with Parkinson's Disease"

Terry Ellis, PhD, PT, NCS
Boston University

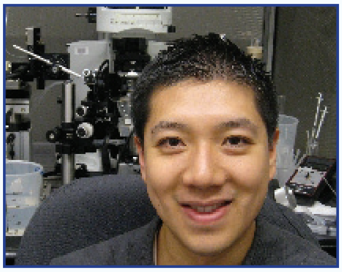
"Mobile Health Technology to Promote Physical Activity in Persons with Parkinson's Disease"

Talene Yacoubian, MD, PhD
University of Alabama at Birmingham

"Effects of 14-3-3s on Alpha-synuclein Release and Toxicity"

Laura Vopicelli-Daley, PhD
University of Alabama at Birmingham

"LRRK2 in Pathological Synuclein Transmission"



C. Savio Chan, PhD
Northwestern University

"Corticostriatal Disruption in a Parkinson's Disease Model"

APDA Scientist Mahlon DeLong Receives Prestigious Award

Scientific Advisory Board member and director of APDA's Center for Advanced Research at Emory University School of Medicine, Mahlon DeLong, MD, has been awarded a 2014 Breakthrough Prize in Life Sciences. Dr. Delong's $3 million award recognizing excellence in research aimed at curing intractable diseases and extending human life, was one of six awarded at a ceremony in Mountain View, Calif., in December.

A professor of neurology at Emory, Dr. DeLong has worked to understand the causes of Parkinson's disease for more than 20 years and has been a pioneer in defining and characterizing the circuits in the brain that malfunction in PD.

Mitophagy: Latest Research Suggests Cell “Poor Housekeeping” Could be a PD Factor

New evidence discovered at the University College London Institute of Neurology and recently published in the journal Nature Neuroscience has linked PD to a genetic defect that interferes with the clearing out process of defective mitochondria, the tiny metabolic generators that supply cell energy. The process, called mitophagy, normally breaks down and disposes the abnormal “cellular power plants,” which if not disposed of can be very harmful.

Members of the research team and the Medical Research Council, which partially funded the study, noted that what makes it so robust is the confirmation of defective mitophagy in a number of different PD models, which raises interesting questions about brain-cell death relating to PD.

Dr. Joseph Freidman, a clinical professor at Brown University School of Medicine and director of APDA’s Rhode Island Information & Referral Center, who likes to use analogies to explain complex scientific programs, explains the process this way.

If a water main breaks in New York City’s Times Square, there will be an enormous traffic jam that begins in Times Square but within minutes spreads north, south, east and west across Manhattan. This soon clogs the exits to the two major highways going north and south on each side of the island, extending the traffic jam.

If you are driving into Manhattan, you’d soon get stuck on the East River Drive and would believe that there’s a problem on this route. Someone on the West Side Highway assumes that there’s a problem on that one since it’s also at a standstill. But the real problem is in Times Square, miles away from either highway stoppage. A driver on each thoroughfare cannot tell where the real problem is, whether Times Square, the highway itself, or an exit ramp. It all looks the same. A spy-in-the-sky satellite will see the results but not the cause.

Similarly, when scientists study brain disease, they can see the big problem and then start searching around for explanations. In PD we have several lines of evidence implicating mitochondrial dysfunction.

Gel Clinical Trial Report Shows Off-Time Reduction

Patients using AbbVie’s levodopa-carbidopa intestinal gel system realized an average reduction in daily off-time of almost two hours, according to a recent report in Lancet Neurology, written by APDA’s Scientific Advisory Board Chairman David G. Standaert, MD, PhD. Dr. Standaert is the chairman of neurology at the University of Alabama at Birmingham, one of the sites for the double-blind, phase III clinical trial.

Dr. Standaert explained that the difference between the gel and a pill, the current standard therapy, is that a pill sits in the stomach for up to six hours waiting to enter the small intestine where it enters the bloodstream to the brain, whereas the gel is delivered directly into the small intestine through a surgically-placed tube.

The study led by the Mount Sinai School of Medicine, N.Y., and preliminary results were first presented in 2012 at the American Academy of Neurology’s annual meeting in New Orleans.

2014 Unity Walk Set for Central Park

Help For Bread And Butter Needs In Chronic Illness

By Julie Sacks

The 2013 Household Financial Planning Survey and Index ranks four types of American households in financial planning issues ranging from Comprehensive Planners to Non-Planners, with the majority (71 percent) falling into the category of Limited or Basic Planners.

Basic and Limited Planners tend to operate their households on a budget and have financial plans around a specific goal such as sending a child to college; whereas Comprehensive Planners take more of a big-picture approach and are generally able to achieve greater financial preparedness.

A PD diagnosis is sure to raise concerns about the future, especially for younger people (those under the age of 55) who worry about potential future earnings loss. People of all ages tend to have questions about Medicare and Medicaid and concerns about financing long-term care.

I frequently suggest that people consult with an elder care attorney and have been surprised by how few people are aware of this legal specialization. Many who do know mistakenly assume elder care attorneys work only with the wealthy and the elderly. In fact, elder law professionals have expertise in special needs law and are adept at guiding people who are managing a chronic illness. They can take then through the process of planning for the future. Other elder law and special needs topics include:

- Age Discrimination
- Health Insurance
- Wills and Powers of Attorney
- Living Trusts
- Special Needs Trusts
- Guardianship

For more information about elder law attorneys or to find one near you, contact the National Academy of Elder Law Attorneys (www.naela.org) or the National Elder Law Foundation (www.nelf.org). If you are not already a comprehensive planner, these websites and a consultation with an elder law attorney can set you on the path to becoming one.

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

FDA Orders Genetic Testing Firm To Discontinue Marketing Plan

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obtain regulatory approval from the FDA that could insure the accuracy of the testing.

In this rapidly evolving era of genetic information about disease risk, both physicians and the public have a great deal to learn. While it can be argued that we all have a right to know our own unique genetic make-up, that knowledge only gives a probabilistic estimate of the degree of risk for a given condition.

Many other variables such as environmental factors and the effects of other genes may modify that probability. For example, the company cannot tell whether you'll develop Parkinson's disease in the next 10 years; it can only tell you whether you are more or less likely, relative to other people.

Professor Hank Greely of Stanford's Center for Law and the Biosciences adds another cautionary aspect to the questions of genetic test "accuracy." While the analytic accuracy of the 23andMe tests may be good (yet to be determined by FDA), Prof. Greely argues that much of the testing lacks clinical validity meaning that results should not be used to diagnose patients. Further, it is sad but true that in many of the conditions/diseases for which 23andMe has provided risk assessments, there are really few validated tools to modify that risk once one is aware of it.

Moving forward, the burden of proof is on 23andMe to demonstrate the analytic accuracy of its DNA testing to the satisfaction of the FDA. Consumers certainly have every right to access information about their risk profile for a variety of diseases. This should best be done, however, in the context of considering the consequences of knowing that you might have a relatively high risk for something bad like Alzheimer's disease or amyotrophic lateral sclerosis (Lou Gehrig's disease). Are you sure that this knowledge would not be, in sum, a negative for your quality of life?

Finally, any decision to act on genetic risk information by changing lifestyle, diet, medications etc. should be done in collaboration with an expert physician or genetic counselor knowledgeable about the specific condition. This would help to ensure that the consumer's assumptions and action plans, if any, are reasonable within the context of our knowledge about the validity of the risk assessment.

Dr. Wooten is a professor emeritus of neurology at The University of Virginia, Charlottesville, and APDA Scientific and Medical Affairs Advisor.

VA Adds Adds Five Illnesses Related to Service-Connected TBI

By Susan Gulas, RN

Some Veterans with traumatic brain injury (TBI) who are diagnosed with any of five other ailments will have an easier path to receive additional disability pay under new regulations developed by the Department of Veterans Affairs.

The new regulations impact some veterans living with TBI who also have Parkinson's disease, certain types of dementia, depression, unprovoked seizures or certain diseases of the hypothalamus and pituitary glands.

The new regulations, printed in the Federal Register, say that if certain veterans with service-connected TBI also have one of the five illnesses, then the second illness will also be considered as service-connected for the calculation of VA disability compensation.

Eligibility for expanded benefits will depend upon the severity of the TBI and the time between the injury causing the TBI and the onset of the second illness. However, veterans can still file a claim to establish direct service-connection for these ailments even if they do not meet the time and severity standards in the new regulations. The final rules can be read at http://www.regulations.gov.

Veterans who have questions or who wish to file new disability claims may use the eBenefits website, available at www.eBenefits.va.gov/ebenefits.

Service members who are within 180 days of discharge may also file a pre-discharge claim for TBI online through the VA-DoD eBenefits portal at www.eBenefits.va.gov/ebenefits.

Information about VA and DoD programs for brain injury and related research is available at www.dvbic.org. Information about VA's programs for Gulf War Veterans is available at www.publichealth.va.gov/exposures/gulfwar/hazardous_exposures.asp.

Susan Gulas, RN is director of APDA's National Veterans Information & Referral Center.

FRAN: A Love Story PD Can Not Alter

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Moe Kornbluth, center, with assistance from his 10-month old grandson Wolf Friel, and daughter Sarah Kornbluth, right, signs a copy of his memoir "Fran" for APDA vice president Stephanie Paul, left.

happening to his very successful, vivacious, and popular wife. "I didn't respond well because she became so different from the person I knew," he says, and the disease progressed so slowly and steadily that it took time to realize that it was altering her personality and cognitive capacities as well as her physical abilities. Only at that point, when he recognized that the cause of his frustration and sometimes anger was her disease, was he able to come to terms and adapt.

Hoping to save people finding themselves in a similar devastating situation that he experienced, Moe has written "Fran," a memoir sharing the impact of PD on a family. "Maybe they can learn from my mistakes, recognize their own weakness, and possibly gain strength and understanding," he says.

Moe says that he never intended the book to be a love story. "I wanted to write Fran's story, one about a strong woman who deserved recognition even at the low point of her life."

For information about the book "Fran," visit APDA's website, www.apdaparkinson.org/fran.

Rhode Islanders Walk with Optimism

Hundreds of Rhode Islanders participate in the 15th Annual Race, Walk & Roll for Parkinson's Disease at Goddard Park, Warwick, bringing the chapter's contribution to almost half a million dollars for research and patient services.

Parkinson Plaza
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- Intestinal gel gets good trial marks

EDUCATIONAL MATERIAL AND PATIENT SUPPORT RESOURCES

APDA’s website www.apdaparkinson.org is the source of many free educational and patient/caregiver support materials. A complete list of booklets, supplements and other publications is available. Most can be downloaded or can be ordered by writing to the national office, calling 800-223-2732 or faxing to 718-981-4399. Free subscriptions to a monthly online newsletter (Digital Digest), a private caregiving coordination service (Lotsa Helping Hands), and an “Ask the Doctor” service are also available.

APDA Information & Referral Centers are the regional patient/caregiver resources for educational materials, physician and social serves referrals, support groups, and programs.

A network list by state is available on the website.

APDA’s National Young Onset Center – www.youngparkinsons.org, 888-223-3801, apda@youngparkinsons.org, addresses the unique challenges to young people with PD and their families.

APDA’s National Resource Center for Rehabilitation – 888-606-1688, rehab@bu.edu, provides direct access to a licensed physical therapist for questions about exercise, information about programs in the caller’s area and educational materials.

APDA’s National Veterans Center – 888-838-6256 ext. 1715, susan.gulas@va.gov, assists active and retired members of the U.S. armed forces with PD and their families.