

(continued from Pg. 3)

There are several different genes that are known to cause PD, but they are rare. The four main genes are:

1. LRRK2 (leucine rich repeat kinase 2)
2. GBA (glucocerebrosidase)
3. Parkin
4. Alpha-synuclein

Presymptomatic testing can be done for these genetic forms of PD, but is only meaningfully performed in the context where a relative who has PD has been genetically tested and is known to carry one of these variants.

How the test works:

A blood sample is collected and sent to a certified DNA testing lab to test for the presence of an alteration in the specific gene in question. In some circumstances, gene tests are done with saliva, but that is not how most certified DNA testing labs do genetic testing.

How certain are the test results?

One complication about genetic testing in the context of Parkinson's disease is that not everyone who has a mutation in one of the genes mentioned above will actually get PD. Specifically, only about 10% of those who have a GBA mutation actually develop PD during their lifetime.

If a gene mutation has already been identified for a specific Parkinson gene, then the test is very specific and accurate only for testing for the presence of that specific mutation. But there is no test to determine whether one will actually develop PD. For this reason, presymptomatic testing in PD is not widely used, and rarely recommended. For families where there is no known mutation in a PD gene, then there is no way to know which gene(s) to test for.

To learn more and submit your own Ask the Doctor questions, please visit www.apdaparkinson.org/ask-the-doctor

APDA wants you to get involved in a deep brain stimulation clinical research study

- Have you been diagnosed with Parkinson's disease for 5 years or longer?
- Are you experiencing disabling Parkinson's disease symptoms or drug side effects despite taking anti-Parkinson's disease medication(s)?
- Are you less than 75 years old?

If you answered "yes" to all these questions, you might be a candidate for a clinical research study, called INTREPID, sponsored by Boston Scientific.

The clinical research study is looking to evaluate the safety and effectiveness of the investigational device Vercise™ Deep Brain Stimulation (DBS) system as an investigational therapy for reducing some of the symptoms associated with Parkinson's disease (PD) that are not adequately controlled with medication.

If you are interested in learning more about this study, please visit: <https://intrepiddb.com/>



To learn about the many ways you can support APDA, please call (800) 223-2732 or visit www.apdaparkinson.org/ways-to-donate.

What's happening at APDA



APDA selected as winner in the 37th Telly Awards The Telly Awards has named APDA as a Silver Telly winner for their PSA entry titled *Live with Optimism*. With more than 13,000 entries from all 50 states and numerous countries, this is truly an honor!

November is Caregivers Awareness Month There are more than one million people living with PD in the United States. For every person with PD, there are family members and friends who give their loving support. This November, show your support for care partners by posting a photo, sending them a card, or taking them out to lunch. Just let them know that their efforts don't go unnoticed. Learn about more ways you can get involved during Caregivers Awareness Month at apdaparkinson.org

Join us for a webinar We invite you to participate in our webinar *Spotlight on Wellness: Staying on Your Feet, Balance Matters* on October 18. You can also check out all of our past webinars at apdaparkinson.org/webinar.

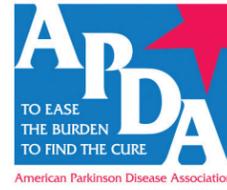
Walk with Optimism

Join us for an Optimism Walk near you! Each of these fundraising events offers a short walk (approximately 1-3 miles) as well as additional support, education, family-friendly activities and most importantly, the chance to bond with others who are similarly connected. The funds raised will enable APDA to continue providing information, education, and support to those impacted by PD and fund scientific research into the causes, prevention, treatments and ultimately the cure.



Fall 2016 Optimism Walks Schedule:
• October 1, 2016: Westport, CT
• October 29, 2016: West Hartford, CT
Stay tuned for the full 2017 Optimism Walk schedule!

For more information, please visit www.apdaparkinson.org/optimism-walks



INSIGHTS

FALL 2016 NEWSLETTER

INSIDE THIS ISSUE:

APDA AWARDS \$1.6 MILLION IN RESEARCH GRANTS

A MESSAGE FROM THE PRESIDENT

DR. VIVEK K. UNNI RECEIVES THE PRESTIGIOUS COTZIAS AWARD

RACING FOR A REASON: MARIE VENTRONE SHOWS HER SPARTAN STRENGTH

ASK THE DOCTOR: Q&A WITH RICHARD H. MEYERS

WHAT'S HAPPENING AT APDA

WALK WITH OPTIMISM

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American Parkinson Disease Association is exempt from Federal Income taxes under Section 501(c)(3) of the Internal Revenue Code.



APDA awards \$1.6 million in research grants

The \$240,000 Cotzias Fellowship has been awarded to Vivek Unni, MD, PhD, Assistant Professor of the Parkinson Center of Oregon, Department of Neurology and Jungers Center for Neurosciences Research at Oregon Health & Science University in Portland, OR.

Funding was also awarded to support three Post-Doctoral Fellowships, seven research grants to junior investigators, eight APDA Centers of Advanced Research, and 12 Summer Student Fellowships.

The grants are awarded through a competitive application process and reviewed by APDA's Scientific Advisory Board (SAB). The SAB is comprised of scientists with a wide array of backgrounds and expertise in all areas relevant to PD research. A scoring process and rigorous review of the applications is conducted by the SAB when it convenes annually to review the proposals. In order to be considered for funding, only applications which meet the highest quality are recommended for approval by the SAB.

"The objective of APDA and the SAB is to invest in the best science," commented David G. Standaert, MD, PhD, John N. Whitaker Professor, Chair of

Neurology and Director, Division of Movement Disorders at the University of Alabama at Birmingham and Chairman of the SAB. "Our aim is to accelerate research and support translational ideas that have the potential to truly improve the quality of life for persons living with PD."

APDA has been a funding partner in most of the major Parkinson's scientific discoveries in the last 50 years including the work of Dr. George C. Cotzias, which led to establishing the effectiveness of Levodopa in treating PD; this treatment remains the gold standard in PD treatment today.

Browse all APDA-funded investigators by visiting www.apdaparkinson.org/apdafundedresearch



APDA Scientific Advisory Board:

(Front row L-R) Marie-Francoise Chesselet, MD, PhD, UCLA David Geffen School of Medicine; Marie H el ene Saint-Hilaire, MD, FRCP (C), Boston University School of Medicine; David G. Standaert, MD, PhD, Chairman of the APDA SAB, University of Alabama at Birmingham, School of Medicine; Mary Maral Mouradian, MD, Rutgers Robert Wood Johnson Medical School; Leslie A. Chambers, President & CEO, APDA.
(Back row L-R) Richard Myers, PhD, Boston University School of Medicine; Un Jung Kang, MD, Columbia University College of Physicians and Surgeons; Dennis W. Dickson, MD, Mayo Clinic, Jacksonville; Joel S. Perlmutter, MD, Washington University School of Medicine; Evan Yale Snyder, MD, PhD, The Burnham Institute; Clemens R. Scherzer, MD, Harvard Medical School and Brigham & Women's Hospital.
(Not pictured); Mahlon R. DeLong, MD, Emory University School of Medicine; J. Timothy Greenamyre, MD, PhD, University of Pittsburgh Medical Center; Laura Marsh, MD, Michael E. DeBakey VA Medical Center

For more information, visit our website at www.apdaparkinson.org, or call (800) 223-2732. To make a donation online, visit www.apdaparkinson.org/FallInsights.



A message from
President and CEO,
Leslie A. Chambers

Dear Friends,

Each May when APDA's esteemed Scientific Advisory Board (SAB) members travel from around the country to meet to review our portfolio of grant applications, I am reminded of how fortunate we are to have this outstanding group of scientists and physicians serving us.

Many of these clinicians and researchers have worked with APDA for decades. At this year's meeting we were especially pleased to recognize the following members for 20 years of commitment: Marie-Francoise Chesselet, MD, PhD, UCLA David Geffen School of Medicine; Dennis W. Dickson, MD, Mayo Clinic, Jacksonville; Richard Myers, PhD, Boston University School of Medicine; and Mahlon R. DeLong, MD, Emory University School of Medicine.

Following a rigorous scoring process, the SAB recommends the list of qualified finalists and their proposals to the APDA Board of Directors for approval. Notifying the finalists of the acceptance of their applications is truly a joyous moment and one that reflects the recognition and support of young investigators in pivotal moments of their scientific careers.

The APDA grant program allows established investigators the opportunity to produce critical pilot data or "proof of concept" results, which then pave the pathway for these scientists to effectively compete for much larger grants typically provided by the National Institutes of Health. We have many examples of these successes. I could not be more proud of this organization for the difference this work makes for those coping with Parkinson's disease, and I could not be more grateful for generous supporters like you for making this all possible.

On behalf of those we serve in the Parkinson's community, my deep thanks to our esteemed colleagues on the SAB and to the next generation of scientists, who I am convinced, will one day soon unravel the mysteries of this disease.

Sincerely,

Leslie A. Chambers
President and CEO
American Parkinson Disease Association

Dr. Vivek K. Unni receives the George C. Cotzias Fellowship



Vivek K. Unni, MD, PhD

"Science thrives on the unexpected – finding that clue that was missed or never seen before in order to make a great, new discovery."

These are the words of Vivek K. Unni, MD, PhD, and the 2016 recipient of APDA's prestigious George C. Cotzias Fellowship. Dr. Unni has spent most of his professional life trying to do just this. For him, it is the most satisfying part of being a scientist and what he believes drives most researchers.

The Cotzias Award will fund Dr. Unni's study of molecular mechanisms of Lewy pathology-associated cell death in PD. Dr. Unni seeks to understand how the protein alpha-synuclein, which at increased levels can directly cause PD.

Funding the best and brightest scientists

APDA initially funded Dr. Unni in 2015 as a Research Fellow on a project geared toward understanding how prion-like protein propagation might be important in PD. *"The main focus of APDA's research program is to fund the best scientists with the brightest ideas to help solve the mystery of PD,"* said Leslie A. Chambers, President and CEO of APDA.

"Dr. Unni exemplifies this profile and we are all extremely pleased to be able to fund his work through the Cotzias Award. We are equally pleased with the ongoing support of our long-time APDA donors who make this work possible."

Dr. Unni applauds APDA for its proven track record of funding exciting, cutting-edge research with dollars that don't exist from any other source. *"APDA supports ideas that are high-risk/high-reward that otherwise may never get tested. Donors are directly influencing the development of novel ideas that can lead to new PD treatments,"* stated Unni.

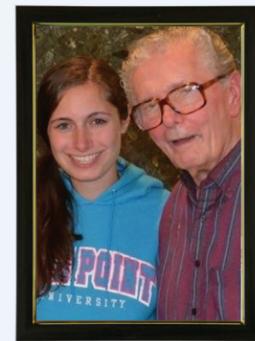
History of the Cotzias Fellowship

Dr. George C. Cotzias was a pathfinder in the pharmacologic exploration of brain functions and in the treatment of PD with Levodopa. APDA established the George C. Cotzias Fellowship in 1979 to honor the memory of this innovator and to stimulate young neurologists to follow his leadership. The esteemed \$240,000 grant is awarded to promising young neurologists to help them establish careers in research and patient care.



Racing for a reason: Marie Ventrone shows her Spartan strength

Marie Ventrone lost her grandfather James Rooney to Parkinson's disease in January of 2016. He was diagnosed 21 years prior to his passing. Aside from a classic tremor and softer voice, he was highly functioning for a very long time.



James is described as a great man who was very involved and giving within the community. He used to make crosses with flowers for gravesites and sell them to raise funds for the church.

Marie is racing for a reason

To honor her grandfather's legacy, Marie started competing in Spartan races. *"Fundraising in memory of my grandfather through 'Spartan's Race for a Reason' allows me to not only raise money for Parkinson's research, but to spread awareness and educate people about the disease,"* says Marie.

When Marie runs she wears a shirt that says "Running to end Parkinson's

disease" with a picture of her and her grandfather captioned: "James Rooney 1940 – 2016." Other runners have responded with words of support and shared their own stories about how Parkinson's disease has affected their lives.

Marie believes that raising awareness is the first step to find a cure. This past summer, Marie competed in a "Spartan Trifecta" – three Spartan obstacle races of varying intensity: Spartan Beast (15.7 miles), Spartan Sprint (3-5 miles), and the Spartan Super (8-10 miles). She raised \$2,855 for APDA in memory of her grandfather!

"I run to fundraise for Parkinson's disease because I'm physically capable of doing so. After watching my grandfather lose his motor functions, I promised myself that I would never take them for granted," says Marie.

Raising awareness to help those living with Parkinson's

Marie and her family got connected with APDA when her grandfather was first diagnosed with PD. *"APDA sent*

our family a great deal of educational materials so we could learn about the disease and how to live with it," she says. *"I feel certain that the funds I raised for APDA will go to good use and help make strides towards finding a cure."*

By spreading the word and competing in future races, Marie hopes to inspire others to take action. *"I encourage others to fundraise and raise awareness for Parkinson's disease so that those living with the disease may benefit from new advancements which may allow the motions of everyday life to be unhindered longer."*

To start your own APDA fundraiser, visit www.apdaparkinson.org/DIYFundraising



Marie competes in Spartan races and has raised \$2,855 for APDA in memory of her grandfather.



Ask the Doctor

A Q&A with Richard H. Myers, PhD, FACMG
PhD Medical Geneticist

Q. My grandmother was diagnosed with PD. My father had the symptoms, but was never diagnosed. In general, only 15% of cases of PD are believed to be hereditary. But, does that percentage go up if there have been two cases (or two generations) that have had PD in my family?

A. There is a lot of research in the area of genetics but still many questions exist that we do not have answers for – but we do know that the risk is very small. We are including some general information on genetics and Parkinson's below. For most people with Parkinson's disease, their disease cannot be attributed to a specific gene. Consequently, for most people who are related to or descended from someone with PD, there is no genetic test that can be performed presymptomatically to determine if they will get PD someday.

(continues on back)

