

APDA LAUNCHES UNSHAKEABLE SPIRIT CAMPAIGN



Bob and Alison Wachstein show their unshakeable determination

During Parkinson's Disease Awareness Month this past April, the American Parkinson Disease Association (APDA) proudly launched a new social media campaign, *unshakeable spirit*. Sparked by the urgent need for increased awareness of Parkinson's disease (PD) and fueled by friends like you, this energizing effort showcases how all across America, people with a PD diagnosis are living a life full of strength and optimism.

Beginning on April 11 — World Parkinson's Day — PD patients, care partners, medical professionals, and supporters participated by sharing content featuring their own photos and inspiring captions created via APDA's "frame generator" to authentically capture and highlight important moments and attitudes that depict their unshakeable spirit. These compelling stories and sentiments that are being shared have been truly inspiring to the Parkinson's community.

By sharing personal stories of triumph, friendship, and determination in the face of PD, we all become stronger. Most importantly, we are showing the world that people with PD and their care partners are not alone in their journey.

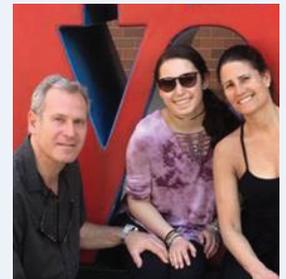
Thank you to everyone who is participating in this movement! The campaign is still going strong and will carry on throughout the rest of the year. We invite you to learn more or to share the story of your unshakeable spirit. Please visit apdaparkinson.org/unshakeablespirit.

"We all want to live life to the fullest, but for people with PD, it might take a little more to get there. A little more drive, a little more optimism and a little more support — and that's the essence of the unshakeable spirit campaign."

— Leslie A. Chambers,
APDA President & CEO

The man behind the movement

When Jeff was diagnosed with early onset PD at 51 years old, he made a decision: he would not allow PD to hinder, discourage, or define him.



One unshakeable family: Jeff and Heather with their daughter, Zoe (middle)

Jeff and his wife Heather co-founded a local APDA support group in Connecticut called "Shakers Anonymous." Through this group he connected with others with whom he could share his journey. Strengthened by those bonds, he was inspired to keep fighting.

"I owe so much to APDA for helping us create our incredible CT support group," says Jeff. "Through the countless stories and shared adventures of fellow group members, I have gained more determination than ever. It's amazing to see the life we can live when we have the support of others."

Jeff is the CEO of innovative marketing company, teamDigital. His compassionate and very talented staff, fueled by a desire to support Jeff and the fight against PD, offered their unique skillset and expertise — free of charge — to APDA. The result? The inventive, engaging and powerful *unshakeable spirit* campaign that is helping raise awareness of PD and the work we do at APDA! teamDigital's kindness and generosity is the perfect example of the unshakeable support that is a key factor to living well with PD.

SHARING OUR UNSHAKEABLE SPIRIT WITH THE WORLD



A message from
President & CEO,
Leslie A. Chambers

Dear Friend,

I hope that this summer you're enjoying some well-deserved time to relax and re-energize! No matter the season, you can rest assured that the American Parkinson Disease Association (APDA) is focused on providing the support, education, and research that will help everyone impacted by Parkinson's disease (PD) live life to the fullest.

As you know, we work tirelessly to bring our mission to life through our outstanding Chapter services and Information & Referral (I&R) Centers. These vital programs offer educational webinars, support groups for veterans, advocacy efforts for people with PD, and exercise classes such as yoga, tai chi, dance and boxing — all great activities for warm summer days.

APDA has also made a commitment to motivate the brightest scientific minds to enter the PD field. We have an excellent track record of supporting researchers who have led the way to crucial insights, discoveries and answers. In order to accelerate these breakthroughs, we encourage people to participate in APDA-funded clinical trials, which are often hosted at our eight Centers for Advanced Research around the country. And, we recently convened our Scientific Advisory Board in May to make important decisions about funding that could change the course of this disease.

We are truly grateful for your partnership, to help us provide the essential information and support that improves the lives of people living with Parkinson's today ... and to accelerate the research that's leading the way to treatments and cures for tomorrow.

Sincerely,

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

We are one community united by friendships, determination and unrelenting spirit. See how people impacted by Parkinson's have told their unshakeable story...and share yours too!



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Chairman of the Scientific Advisory Board, David G. Standaert, MD, PhD
President & CEO, Leslie A. Chambers

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

Follow APDA on Facebook and Twitter to see more inspiring stories. Create and share your own framed photo at apdaparkinson.org/unshakeablespirit.

APDA-FUNDED RESEARCH SHEDS LIGHT ON KEY FACTORS OF PD



Dr. Laura Vopicelli-Daley, recipient of an APDA research grant

Thanks to a cutting-edge study funded by APDA and pursued by Laura Vopicelli-Daley, PhD, at the University of Alabama at Birmingham, today we have even greater insight into the inner workings of Parkinson's disease (PD).

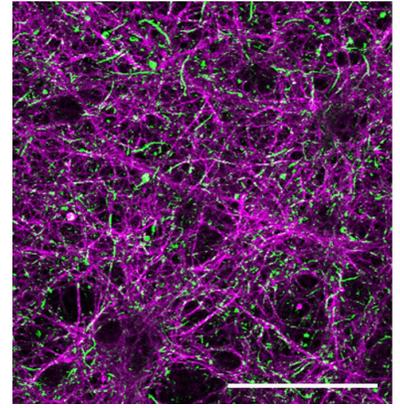
Dr. Vopicelli-Daley's work focused on the impact of mutant LRRK2 (the most common genetic cause of PD) on the formation of abnormal aggregates of alpha-synuclein (the protein that accumulates in all cases of PD). She wondered: *could this study lead us to a method of preventing accumulations of alpha-synuclein in the brains of PD patients and help prevent the progression of the disease?*

Along with Dr. Andrew West, an expert on LRRK2, Dr. Vopicelli-Daley discovered that LRRK2 does in fact increase alpha-synuclein formation of alpha-synuclein aggregates, particularly in a susceptible brain region called the substantia nigra pars compacta. This brain region has dopamine neurons that die in PD. The study found that LRRK2 kinase inhibitors, which are being developed for clinical trials, reduce the formation of these aggregates. We are hopeful that this finding could be of great significance in unlocking the mysteries of PD.

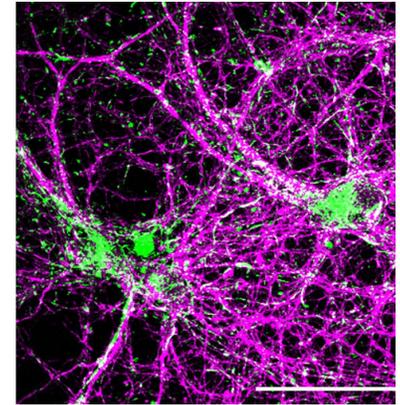
"This work is really important because it 'connects the dots' between two important factors in the cause of PD: alpha-synuclein and LRRK2," states David G. Standaert, MD, PhD, Chair of the APDA Scientific Advisory Board, John N. Whitaker Professor and Chair of Neurology, and Director of the Division of Movement Disorders at the University of Alabama at Birmingham. *"These results are certain to accelerate work on drugs to block LRRK2, which may be a means of slowing or stopping the progression of the disease."*

APDA is proud to fund critical research like this and to encourage the work of scientists who have devoted their careers to uncovering treatments and ultimately a cure for PD. To learn more about our research impact, visit apdaparkinson.org/research.

WT-LRRK2



G2019S-LRRK2



Primary hippocampal neurons from mice expressing wild type, normal LRRK2 or mice expressing the PD-associated G2019S-LRRK2 mutation were exposed to alpha-synuclein fibrils. Inclusions resembling Lewy neurites and Lewy bodies found in PD brains are visualized as green and neuronal axons are visualized as magenta. More inclusions are apparent in the mice expressing G2019S-LRRK2 compared to the neurons with normal LRRK2.

TIPS FOR CARE PARTNERS

In addition to impacting those diagnosed with the disease, Parkinson's can significantly affect loved ones. To keep care-partnering relationships healthy and balanced, it's important for care partners to maintain their own well-being. Here are some tips that can help:



Find support.

You're not alone! Find a Care Partner Support Group. APDA Chapters and Information and Referral (I&R) Centers offer many programs for care partners.



Accept help.

Remember you are only one person! Set realistic goals and focus on what you're able to provide. Don't be afraid to reach out for extra help with duties.



Maintain your own social life.

Social support is important, even if it just means a walk each week with a close friend or family member.



Take care of your own health.

Taking care of others is much more difficult if your own health needs aren't met. Exercise, plan activities, and fuel your body with nutritious food.



Manage your stress levels.

Relaxing is not only important for you, but for the loved one you care for. It will allow you to think more positively and maintain a healthy mindset.

ASK THE DOCTOR

Q&A

with Marie H el ene Saint-Hilaire, MD, FRCP (C),
Boston University School of Medicine



Dr. Marie H el ene Saint-Hilaire, Medical Director at Boston University School of Medicine, an APDA Information and Referral (I&R) Center, and member of the APDA Scientific Advisory Board

Q. I'm 64 years old and I have PD. I was in the final steps for getting Deep Brain Stimulation (DBS), but then my heart failed. I'm getting ready to pursue DBS again, but I need to know: does it help with psychosis and cognitive problems?

A. While DBS can result in many benefits, the procedure does not directly improve cognitive problems and psychosis.

Some individuals have cognitive problems and psychosis as a result of their PD medications. If DBS improves their motor symptoms enough that less medication is required, these symptoms may subside with the reduced dosage. For others who have cognitive problems and psychosis as a direct result of PD, DBS will not improve these symptoms.

It is important to discuss this treatment option with your neurologist and DBS team so that they can perform a careful screening of your general physical and mental health to determine if you are a good candidate for DBS.

Q. Are delusions common for those with PD? What are the causes and treatments?

A. While it is not among the more common symptoms, approximately 5% of individuals with Parkinson's experience delusions, often accompanied by visual hallucinations without insight (psychosis). Psychosis is usually observed in advanced stages of PD, or with long-term use of PD medication. Infections and anesthesia can also precipitate a confused state.

It is not fully understood why some individuals experience these symptoms. Treatment may involve one or more of the following: adjusting PD medications, using antipsychotic medications, or offering support to the patient and family to ensure comfort and safety. Treatment must be administered under the care of a physician, and any changes in behavior should be reported.

An excellent resource for more information on this subject is the book *"Making the Connection between Brain and Behavior: Coping with Parkinson's Disease"* by Joseph H. Friedman, MD, APDA Medical Director at Kent Hospital in Warwick, RI.

Q. I recently was hospitalized to bring down my then-daily dose of Sinemet to 2800 a day. The first 24 hours I was given no Sinemet. Then 2 days of 300 Sinemet. Then 1600 Sinemet for two days, then released. Is this a standard practice or how you would lower the Sinemet dosage for a now 18-year Parkinson's patient?

A. There is not one standard way to decrease medication doses. It depends on many factors including the amount of medication as well as an individual's side effect profile and response to each dose. It is important to regularly communicate with your physician on how you are currently doing on a lower dose. Titration is done to get the best response to medication with the smallest amount of side effects. This is sometimes done in the hospital to allow for closer monitoring of symptoms as medication is decreased.

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What's happening at



Join us for an Optimism Walk

The Optimism Walk — APDA's signature fundraising event — is part of a nationwide movement to mobilize and inspire people to step up and help put an end to PD. Optimism Walks are being held in 15 locations across the country and the season is underway! Register for a walk near you or show your support with a donation at apdaparkinson.org/optimism-walks.



Watch an educational webinar

APDA's webinar series covers a variety of interesting and helpful subjects that are relevant to the PD community, including: managing symptoms, playing an active role in your treatment plan, important information on clinical trials, and improving overall well-being. Join us for an upcoming webinar or watch recently archived presentations at apdaparkinson.org/webinar.



See APDA's impact in 2016

We've done some truly incredible work over the past year, from expanding our support services and educational resources, to investing \$1.6 million in life-changing research. For a comprehensive overview of all we've accomplished with your help, read our 2016 Annual Report at apdaparkinson.org/financial-reports.