

NEW SMARTPHONE-BASED SYSTEM COULD HELP PEOPLE WITH PARKINSON'S DISEASE (PD)

Postural instability, a core symptom of PD, can lead to issues with balance and increase the risk of falling. This can be discouraging and even dangerous for people with PD who are trying to maintain their independence — and that's why Dr. Beom-Chan Lee is working on an effective, accessible program that can counteract this symptom.

Seeing the shortcomings of other training program options, many of which are impractical for in-home use, Dr. Lee and his team applied for and received a grant from the American Parkinson Disease Association (APDA) to make urgently needed improvements to this area of PD treatment. *"We wanted to develop a system that can be easily and readily used in a home environment,"* says Dr. Lee. And they went on to do exactly that.

Dr. Lee Develops Accessible Solution for Postural Instability

With APDA's funding, Dr. Lee led the development of a small, lightweight, and easy-to-use smartphone-based system called the Smarter Balance System (SBS). This wearable technology allows people with PD to self-correct as they perform physical therapist-recommended balance exercises at home — a far better alternative than exercising without guidance.

Alberto Fung, a graduate student involved with the study, explains, *"It's almost acting as if a physical therapist is with them, guiding them."*

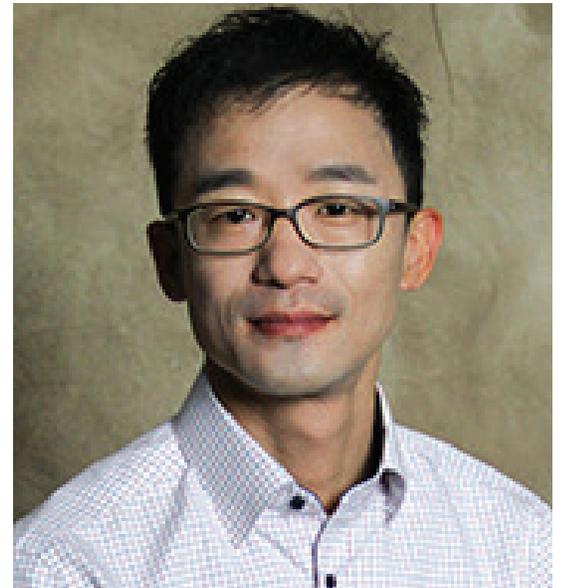
After a promising preliminary study, Dr. Lee and his team are now focusing their efforts on in-home studies, during which participants will take balance performance assessments to determine the efficacy of the SBS. The scientists behind this system are optimistic that improvements in balance will be retained for months after extended balance training with the SBS.

Hope for a More Independent Future

If successful, the SBS could be a game-changer for people with PD who struggle with postural instability. With a program they can use from the comfort of their own home, they can train every day with ease. And when they have greater control over their balance, they will have more confidence as they go through their daily lives.

The SBS also has the potential to reduce the need for assistance by care partners because people with PD will be able to improve their balance on their own. In this way, the SBS could help them become more independent and live life to the fullest.

We are thrilled by the innovations that Dr. Lee and his team are making with the SBS. And we are grateful for your support of APDA researchers, who are taking us one step closer to a brighter future for the PD community.



Dr. Beom-Chan Lee, assistant professor at the University of Houston Department of Health and Human Performance, is creating a smartphone-based system to counteract postural instability in PD.

“Aided by a research grant from APDA, we took a major step toward developing technology that can improve the lives of people with PD.”

— Dr. Beom-Chan Lee



A message from
President & CEO,
Leslie A. Chambers

Dear Friend,

Spring is here, bringing with it a renewed sense of hope and optimism! I want to share with you some of the great progress we're making, thanks in large part to friends like you.

Your donations have supported innovative research into a smartphone-based system that could improve balance control for people with PD and training programs at the Washington University School of Medicine for the next generation of PD researchers.

We are also thrilled to announce the release of our new Public Service Announcement (PSA) campaign in April, which will serve to spread awareness of PD and show the unshakeable spirit and determination of those living with this disease.

Thank you so much for your generosity, which made these achievements possible! I hope we can count on your continued support in 2018.

Sincerely,

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

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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.

APDA WELCOMES NEW VICE PRESIDENT CHIEF SCIENTIFIC OFFICER



Rebecca Gilbert, Vice President,
Chief Scientific Officer

APDA proudly welcomes Rebecca Gilbert, MD, PhD, in the newly-established role of Vice President, Chief Scientific Officer. In this position, Dr. Gilbert will be responsible for APDA's annual organizational research strategy, planning and funding in conjunction with APDA's Scientific Advisory Board (SAB) Chairman, Dr. David G. Standaert. Dr. Gilbert will serve as the lead liaison

to the SAB and will oversee the research grants program including funding to APDA's Centers for Advanced Research; as well as the creation, management and ongoing evaluation of all scientific materials and communications, both internal and external to APDA.

"We are excited to have Dr. Gilbert join the APDA team. Her practical and relevant medical knowledge will be critical in allowing APDA to deliver its urgent mission and further solidify APDA's position as the largest grassroots organization serving the PD community nationwide," stated Leslie A. Chambers, APDA President & CEO.

Prior to joining APDA, Dr. Gilbert was Associate Professor of Neurology at the Fresco Institute for Parkinson's and Movement Disorders at NYU Langone Medical Center in New York City. In this role, she saw movement disorder patients at both NYU and Bellevue Hospital Center, initiated and directed the NYU Movement Disorders Fellowship, participated in clinical trials and other research initiatives for PD, and lectured widely on the disease.

Dr. Gilbert holds an MD from Weill Medical College of Cornell University and a PhD in Cell Biology and Genetics from the Weill Graduate School of Medical Sciences. She completed her Neurology Residency as well as her Movement Disorders Fellowship at Columbia Presbyterian Medical Center.

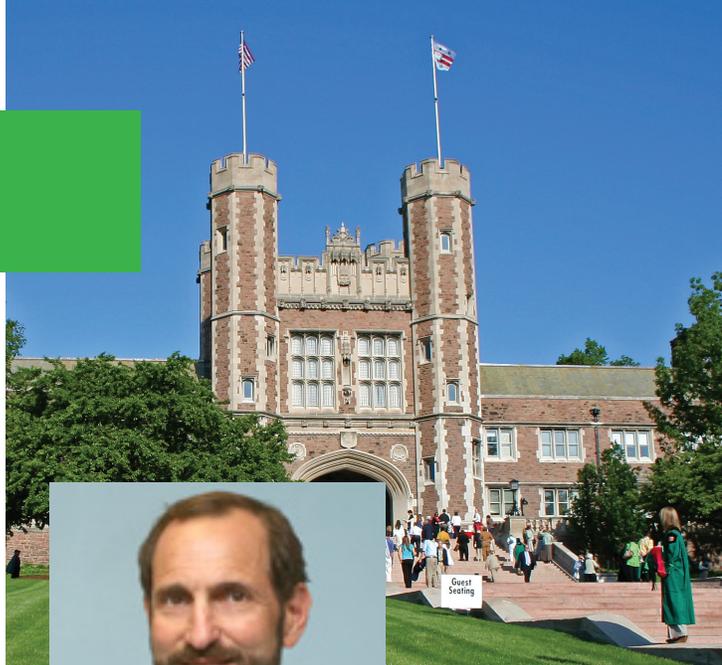
Dr. Gilbert has hit the ground running and will be the featured speaker for APDA's next Spotlight Webinar/Teleconference program entitled **Enhancing Your Communications About Off** on May 9, 2018, from 1:00-2:00 p.m. EST.

on: WASHINGTON UNIVERSITY
SCHOOL OF MEDICINE

APDA funds eight Centers for Advanced Research across the country, which facilitate investigations into the causes, treatments, and ultimately, a cure for PD.

One of these centers is located at the Washington University School of Medicine in St. Louis, MO, where APDA funding supports:

- **Pilot data for seven RO1 grants currently funded by the National Institutes of Health**
- **Studies on biomarkers for PD and cognitive impairment occurrence**
- **Exercise studies, emphasizing gait and balance**
- **More than 4,000 PD patient visits per year**
- **Epidemiologic studies (including risk factors for parkinsonism) headed by Dr. Brad A. Racette, Executive Vice Chairman of Neurology**



Joel S. Perlmutter, MD,
Director of the APDA Center
for Advanced Research at
the Washington University
School of Medicine

Training the Next Generation of PD Researchers

At the Washington University School of Medicine, Dr. Joel S. Perlmutter leads a two-year fellowship program for scientists focused on movement disorders. The training plan encompasses basic and translational research, as well as a patient oriented approach.

APDA is grateful for Dr. Perlmutter’s efforts over the past 20 years, which have given fellows the opportunity to gain the clinical skills they need to pursue PD research.

Your generous donations help fund APDA’s Centers for Advanced Research, where experts like Dr. Perlmutter are encouraging the best and brightest young scientists to enter the field of PD research. Thank you for supporting these essential fellowship programs!

APDA TO RELEASE INSPIRING NEW PUBLIC SERVICE ANNOUNCEMENT

This April, APDA will be releasing a new public service announcement (PSA) that will be featured in English and Spanish on television and in a social media campaign all across the country. We are confident that this PSA will expand the public’s understanding of the disease and give hope to those already impacted by PD.

Most people take PD at face value, associating it only with symptoms such as facial masking, tremors, and old age. But we know that there is more than meets the eye — there are invisible symptoms; people under the age of 40 are affected; and there are one million Americans who are fighting PD with everything they have.

With this PSA, entitled “Look Closer”, we will show the unshakeable spirit and determination that it takes to live life to the fullest with PD, as well as the unshakeable support that gives strength to people facing this disease. We are thrilled to share our message with Americans everywhere, bringing awareness to PD and instilling optimism in everyone affected by this disease.



Christian Banda, diagnosed with PD at age 34, prepares for his scene. The PSA was shot at The Altman Building in New York City. Special thanks to Ken Ruby and The Altman Building staff who generously donated use of the space for the two day PSA shoot in February.



Ask the DOCTOR



Q & A

with Marie H el ene
Saint-Hilaire, MD, FRCP (C)

Dr. Marie H el ene Saint-Hilaire, Medical Director of the APDA Information & Referral Center and Center of Advanced Research Boston University, APDA Scientific Advisory Board member

Q. My husband has Parkinson's disease. Sometimes, his voice becomes soft and quiet in the evening, but it returns to normal by the next morning. However, this last occurrence has lasted a full week. Do you think this symptom could have been aggravated and prolonged by some other trigger?

A. Typically, individuals with PD will experience one or more of the following voice-related symptoms:

- Voice is quiet, weak, or drowned in noise
- The rate of speech is too fast
- Words are difficult to distinguish
- Stuttering
- Loss of breath when talking
- Lack of emotional tone

Fatigue may also make voice symptoms worse. A speech and language pathologist (speech therapist) can be quite helpful in not only evaluating the voice, but also providing treatment strategies. A referral from your husband's neurologist or primary care provider is required. Be sure to share these symptoms with the doctor to best determine if it is a PD symptom or due to another cause.

What's happening at APDA



Optimism Walks are Approaching

Be a hero to your local PD community by registering for an Optimism Walk! The 2018 season is underway with Walks being held across the country through October. The more funds we raise, the more people we can help — you can make that happen! For cities and dates, visit apdaparkinson.org/optimism-walks. Join us!

APDA to Participate in 2018 Unity Walk

APDA is proud to be a part of the 2018 Parkinson's Unity Walk on April 28 taking place in New York City's Central Park. 100% of donations support research funded by five major Parkinson's foundations, including APDA. In addition to raising awareness and funds for research, this will also be a day of community and education. Get more details on this event by visiting www.unitywalk.org

