

NEW INFORMATION & REFERRAL CENTERS SUPPORT PD COMMUNITIES NATIONWIDE

APDA is thrilled to announce the opening of three new Information & Referral (I&R) Centers across the country! In San Francisco, CA; Vernon, CT, and Chicago, IL, we are expanding the reach of our vital services to people with Parkinson's disease (PD) and their care partners.

As a grassroots organization that's powered by dedicated professionals and members of the PD community, our network of I&R Centers couldn't be more essential. At each Center, people with PD and their families access reliable information and education, participate in health and wellness activities, and find comfort in having a place to turn to for answers and support.

And now, with a total of 22 I&R Centers nationwide, APDA will be able to help more people with PD than ever before.

APDA's I&R Centers provide:

- Information and healthcare referrals
- Educational symposiums for people with PD and their care partners
- Support programs led by professionals and trained peers
- Health and wellness activities like: tai chi, yoga, stretching, boxing and dance
- Events, services, and resources to facilitate a better quality of life for the PD community

Thank you for your generosity — which made this expansion of APDA's services possible. Because of you, more Americans with PD will have access to essential support and resources so they can live life to the fullest.

“We at APDA are proud of the positive impact our Information & Referral Centers have made in the lives of Americans facing Parkinson's. We can't wait to share this critical resource with even more of our friends and neighbors in California, Connecticut and Illinois!”

— Leslie A. Chambers, President & CEO



San Francisco, CA

University of California
San Francisco
Movement Disorder and
Neuromodulation
Center Medical Directors:
Ian Bledsoe, MD and
Jill Ostrem, MD



Chicago, IL

University of Chicago
Department of Neurology
Medical Director: Tao Xie,
MD, PhD



Vernon, CT

Hartford HealthCare
Chase Family Movement
Disorders Center
Medical Director: J.
Antonelle de Marcaida, MD

APDA delivers education, support, and patient services to Americans with PD and their families each day. To find an APDA Information & Referral Center near you, visit www.apdaparkinson.org/community.



A message from
President & CEO,
Leslie A. Chambers

Dear Friend,

Now that the sun is out, it's time to take advantage of all the fun outdoor activities that this season has to offer! For people with PD, summer can be the perfect time to start new healthy habits that help them live life to the fullest, like yoga, swimming, cycling, and dancing. Just don't forget your sunscreen!

This is also an especially exciting time for the PD community because APDA has just opened three new Information & Referral Centers across the United States, offering help and support to people in Connecticut, California, and Illinois. And in the field of science and research, we welcome two accomplished PD experts to join our Scientific Advisory Board, which makes crucial decisions about research funding.

Thank you for your support this year as we continue our tireless efforts to help people with PD live life to the fullest. We are so grateful for compassionate friends like you!

Sincerely,

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

TWO PD EXPERTS APPOINTED AS NEWEST SCIENTIFIC ADVISORY BOARD MEMBERS

Meet the newest members of APDA's Scientific Advisory Board: Jill Ostrem, MD and Vivek K. Unni, MD, PhD. Seats on APDA's SAB are reserved only for the best and brightest in the field and we couldn't be more pleased to welcome these two astounding professionals who have already made incredible contributions in the fight against PD.

As SAB members, Dr. Ostrem and Dr. Unni will play an integral role in the future of PD research. They will review grant proposals, help to determine and recommend projects that should receive funding, and participate in selecting scientists for awards. It is a position that requires expert knowledge of the disease, as well as a commitment to improving the lives of people with PD, and Drs Ostrem and Unni are a tremendous addition to the team.

Jill Ostrem, MD

UCSF School of Medicine, San Francisco, CA



Dr. Ostrem is the medical director of the Movement Disorder and Neuromodulation Center at the University of California San Francisco. She specializes in the medical and surgical treatments of movement disorders such as PD, essential tremor, and dystonia.

She is particularly interested in treatments such as deep brain stimulation and gene therapy, as well as the use of neurotoxins.

"I am honored to join APDA's Scientific Advisory Board. This is an exciting time in our mission to find the causes of PD, discover better treatments, and improve the lives of patients and families who have PD."

— Jill Ostrem, MD

Vivek K. Unni, MD, PhD

Oregon Health & Science University, Portland, OR



Dr. Unni is an assistant professor in the Parkinson Center at Oregon Health & Science University (OHSU). As a physician, he cares for patients impacted by PD. In 2017, he was awarded APDA's prestigious George C. Cotzias research fellowship, a \$240,000 grant awarded over a three year period.

We offer our deepest thanks to Marie-Francoise Chesselet, MD, PhD Charles H. Markham Professor of Neurology Emerita, David Geffen School of Medicine at UCLA, who has retired after more than 20 years of participation on the APDA Scientific Advisory Board. Dr. Chesselet's contribution as an active Board member will be missed.



Published quarterly by the American Parkinson Disease Association
135 Parkinson Ave., Staten Island, NY 10305 (800) 223-2732
apda@apdaparkinson.org | www.apdaparkinson.org
Chairman of the Board of Directors, Patrick McDermott
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.

Spotlight

on:

BOSTON UNIVERSITY SCHOOL OF MEDICINE

APDA funds eight Centers for Advanced Research across the country which facilitates investigations into the causes, treatments, and ultimately, a cure for PD. One of these centers is located at the Boston University School of Medicine in Boston, MA, where APDA funding supports:

- Biomarker studies
- Studies of non-motor symptoms
- Studies of self-management strategies in PD
- Active clinical trials
- 3,500 PD patient visits per year
- Deep Brain Stimulation program

APDA Rehabilitation Resource Center Offers Help and Information to People with PD

Together, APDA and Boston University established the country's very first National Parkinson's Rehabilitation Resource Center — a place where anyone with PD can access reliable information and exercise recommendations.

Under the direction of Dr. Terry Ellis, an assistant professor at Boston University, the Center aims to share knowledge with patients, caregivers, students and healthcare professionals to help everyone impacted by PD live life to the fullest.

“Exercise is a vital part of the treatment of Parkinson's disease. People with Parkinson's who exercise regularly have better function and quality of life compared to those who don't exercise. Sometimes the information about which kind of exercise to do and how much to do can be overwhelming. We are here to help people with Parkinson's, family members and healthcare professionals get accurate and current information about exercise.”

— Terry Ellis, PhD, PT, NCS



Marie Hélène Saint-Hilaire, MD, FRCP (C), FAAN, Professor of Neurology, Medical Director of the APDA Information & Referral Center and Center of Advanced Research Boston University, APDA Scientific Advisory Board member.

“Generous support from APDA for our Center of Advanced Research has allowed researchers across Boston University to conduct pilot studies addressing many unmet needs. Research is ongoing to identify biomarkers and develop treatments that address motor and non-motor problems. During the past decade important collaborations across disciplines have been fostered and have successfully led to increased funding from NIH and other agencies. We could not do this work without funding from APDA.”

— Marie Helene Saint-Hilaire, MD

DEDICATED WISCONSIN FAMILY RAISES CRITICAL FUNDS SINCE 2012 TO SUPPORT APDA PROGRAMS AND EDUCATION



For the family and friends of Bob Nasett who was diagnosed with Young Onset PD over a decade ago, Parkinson's Awareness month in April is the time when they really show the strength of their unshakable community. Since 2012, this dedicated group of Wisconsinites have organized the *Parkinson's Half Marathon & 5k* just outside of Madison and have raised collectively more than \$325,000. These critical funds benefit the Wisconsin Chapter of APDA to support their programs and public education.

This year's event held on April 7, brought record cold. But the frigid temperatures did nothing to deter more than 1,300 runners and walkers from turning out to participate. The warmth of friendship and dedication shared by volunteers, participants, and their supporters created an atmosphere of celebration long after the last runner crossed the finish line.

Ask the DOCTOR

Ask the

Q&A

with
Terry Ellis, PhD, PT, NCS



Dr. Terry Ellis, Assistant Professor at Boston University College of Health & Rehabilitation Sciences, Director of the Center for Neurorehabilitation, Advisor for the APDA Massachusetts Chapter.

Q. What is the best kind of exercise for Parkinson's?

A. There are several types of exercise that are important for people with Parkinson's disease. Aerobic exercise, strengthening, balance and stretching exercises are all recommended. Aerobic exercise is important for fitness and may reduce PD symptoms. Strengthening exercises are important to improve muscle function and to reduce PD symptoms related to slowness or bradykinesia. Balance exercises are important to reduce fall risk and stretching exercises may reduce stiffness and improve mobility.

Q. How do I get started on an exercise program?

A. To get started on an exercise program, you can go to the APDA website www.apdaparkinson.org/resources-support/download-publications/ and download an exercise booklet called "Be Active & Beyond." This is a free booklet containing information about exercises, pictures of exercises and exercise instructions. We also recommend that you consult with a physical therapist with expertise in PD. A physical therapist can work with you to develop an exercise program tailored to your needs. If you need help finding a physical therapist in your area who is knowledgeable about PD, feel free to contact us at this toll free number: 888-606-1688 or you can e-mail us at rehab@bu.edu.

MATCHING GIFTS can double your gift to APDA!

Many employers sponsor matching gift programs and will match most charitable contributions made by their employees. Gifts from retirees and spouses may also qualify for a match. Visit our matching gift page at www.apdaparkinson.org/get-involved/ways-to-give/matching-gift-program to find out if your company will match your donation!

What's happening at APDA



Look Closer

In April APDA launched a brand new public service announcement (PSA) that encourages viewers to *Look Closer* at PD. Most people take PD at face value, associating it only with the more commonly-known physical symptoms such as tremors and slow movements. But often there is more than meets the eye. APDA is urging people to see the people behind the disease, to see the unshakeable spirit and determination that it takes to live life to the fullest with PD. Featured nationwide on television (in English and Spanish) and in a social media campaign, *Look Closer* will expand the public's understanding of the disease and give hope to those already impacted by PD. The campaign also features a video library on the APDA website which showcases the people in the PSA as well as inspirational stories submitted by the public.

APDA to Host 2nd Annual West Coast Parkinson's Forum in Southern California

October 20-21, 2018, APDA will host a weekend of education and inspiration in Irvine, CA for people with PD and their care partners. Over the course of two days, attendees will learn about the latest in PD treatment and research, try out some movement and exercise demonstrations, connect with others who are traveling on the PD journey, and enjoy an evening of dinner and dancing! Visit www.apdaparkinson.org/westcoastforum to register for this special weekend of education, respite and relaxation.

APDA Launches Planned Giving Online Portal

We are tremendously grateful to those who have chosen to leave a lasting legacy by including APDA in their planned giving. If you are considering planned giving, APDA just made your access to this important information even easier with a newly-launched online portal. Donors now have the option to use an interactive tool called *Find Your Best Gift* where you may compare giving options, download print-ready materials, and access our Estate Planning Guide. To learn more, visit our Planned Giving Online Portal today at pg.apdaparkinson.org.