

INTRODUCING DR. BRIAN L. HARPER: MEMBER OF APDA'S NEW DIVERSITY STRATEGY COMMITTEE

The American Parkinson Disease Association (APDA) is proud to welcome Dr. Brian L. Harper to the newly formed Diversity Strategy Committee, which will expand on APDA's educational materials, methods and delivery mechanisms to reach underserved audiences.

As the Medical Director of the APDA Information & Referral Center at the New York Institute of Technology in Old Westbury, NY, Dr. Harper brings a wealth of expertise to the committee. He is a colleague of Dr. Harold Freeman, who was the founding pioneer of patient navigation. Dr. Harper worked alongside Dr. Freeman in promoting this model of care at the Ralph Lauren Center for Cancer Care & Prevention in Harlem, NY.

Dr. Harper's engagement will enhance APDA's efforts to identify patients not accessing quality PD care, and to learn how we can most effectively extend our vital services to those groups.

Identifying Key Issues for Diverse PD Populations

Dr. Harper has seen how poorer communities, African Americans, and Latinos are provided lower quality of medical care than the general population. He was eager to learn if these same disparities affect the lives of PD patients.

"My involvement in APDA's I&R Center and participation on this diversity committee compelled me to look more closely at PD," Dr. Harper says. *"Social determinants, including culture, can have a major impact on health. In the U.S. we are so culturally diverse, that it is important to have an understanding of how diseases can manifest in different communities."*

The Diversity Strategy Committee has identified some key initiatives that will inform the way health disparities in the PD community are addressed. According to Dr. Harper, the two main issues are awareness of PD in certain populations, and physicians' understanding of the disease.

Leading the Way to Improved Outcomes for PD Patients

Dr. Harper believes that we can spread awareness of PD more effectively by rethinking the way we talk about the disease and targeting populations that don't typically receive this kind of information.

"We need to tailor our messages to a given community to make them aware of PD and encourage them to see a clinician," he says.

The committee also aims to ensure that, once patients see their clinicians, they are given accurate diagnoses and referrals to specialists so that they can start on the path to the best possible outcomes.

"We want to make sure that our local clinicians are educated about PD, how to make a diagnosis, and what resources are available to help," explains Dr. Harper.



Brian L. Harper, MD, MPH, APDA Information & Referral Center Medical Director at the New York Institute of Technology and APDA Diversity Strategy Committee member

We are confident that, with experts like Dr. Harper by our side, we can help more people with PD access the care needed to live life to the fullest.



A message from
President & CEO,
Leslie A. Chambers

Dear Friend,

We are so excited to begin another year of hope and optimism with friends like you! Thanks to your support, we at APDA are the boots on the ground, serving people impacted by PD all across the country.

As you may know, PD is not a “one size fits all” disease — it touches each life differently. There is also a wide range in access to care across gender, ethnicity, socioeconomic status, and geographic areas. For example, in the U.S., PD rates are noticeably higher in the midwest and northeast regions. In 2018, we aim to address these health disparities for Americans with PD.

We are only able to carry out this important work because of your donations to APDA. We are so grateful for your generosity and look forward to your continued partnership in 2018!

Sincerely,

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

APDA HOSTS WEEKEND OF EDUCATION AND INSPIRATION

APDA hosted its first-ever Parkinson’s Educational West Coast Forum in October. For two days, attendees received the latest information about PD and were treated to some special activities meant for respite and relaxation. We assembled some of the best and brightest minds in the area of PD to present the most current and pressing information about research, treatments and to answer questions from those on their PD journey.

In addition to plenary sessions and panel discussions there were also breakout sessions on topics like *Your Sleep & PD* and *Early Management of PD* as well as a special session for care partners. To balance out the weekend, attendees were treated to complimentary chair massages and hair and make-up touch ups prior to a fun evening of dinner, dancing and socializing.

The weekend ended with an inspirational presentation and Q&A featuring Allison Toepperwein, who was diagnosed at age 37 and used her diagnosis as motivation to live her best life. Upon hearing that she would benefit from exercise, she not only began working fitness into her life, she charged forward full-force and became a two-time contestant on TV’s *American Ninja Warrior!* An incredible role model to her young daughter, to her fellow people with PD, and to all of us, Allison’s story and positive attitude was the perfect close to an incredible weekend.



(R-L) APDA President & CEO Leslie A. Chambers moderates panel discussion about current PD research featuring Beate Ritz, MD, PhD, David Geffen School of Medicine at UCLA, Echo Tan, MD, Cedars-Sinai, and Natalie Diaz, MD, Harbor – UCLA Medical Center.

“The APDA Forum was terrific in all respects – the speakers and their information, the incredible Allison Toepperwein, learning what leadership is all about ... It was the best event I have ever been to!” – David Bunch, Attendee

APDA works tirelessly every day to provide the education, support and research that will help everyone impacted by PD live life to the fullest and the West Coast Forum is just one way we are doing just that. Attendees left the weekend armed with a wealth of information to help them better navigate their life with PD and we look forward to bringing more programs like this to our PD community around the country.

The program was generously supported by our presenting sponsors: AbbVie, Acadia and Sunovion.

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.

on: RUTGERS ROBERT WOOD JOHNSON MEDICAL SCHOOL



Lawrence I. Golbe, MD, Medical Director of the APDA Center for Advanced Research at the Rutgers Robert Wood Johnson Medical School

Dr. Golbe and Team
Discover a Key Mutation in PD

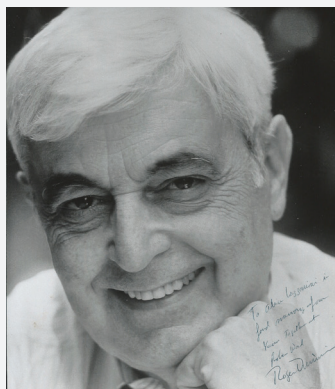
Dr. Golbe led a team at Rutgers Robert Wood Johnson Medical School that discovered a family with autosomal-dominant PD in 1987. They extended the family tree through painstaking genealogical and clinical work to include 61 affected members. In 1997, in collaboration with the National Human Genome Research Institute at the NIH, they published the first report of a mutation in the gene for alpha-synuclein in PD, naming it PARK1. Much of that work was supported by their APDA Center Grant.

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 Rutgers Robert Wood Johnson Medical School in New Jersey, where APDA funding supports research in:

- **The role of TG2 in the pathologic aggregation of alpha-synuclein**
- **L-dopa induced dyskinesia, atypical parkinsonism, progressive supranuclear palsy**
- **Neuroprotective activity of a non-caffeine component of coffee**

Donations from generous friends like you help fund APDA's Centers for Advanced Research, where scientists are pushing the boundaries of PD research every day. Thank you for fueling our efforts to unlock the mysteries of this disease!

IN MEMORIAM



ROGER C. DUVOISIN, MD

July 27, 1927 — October 5, 2017
Professor Emeritus and Chair,
Department of Neurology,
Rutgers Robert Wood Johnson
Medical School 1979-1996

Dr. Roger C. Duvoisin, a neurologist who played a leading role in making PD treatment breakthroughs and discovering the genetic roots of the disorder, passed away on October 5, 2017. Dr. Duvoisin served as member of the APDA Scientific Advisory Board from 1991-1997, taking the Chairmanship from 1995-1997. He was the recipient of the APDA Fred Springer award in 1992 and the Roger C. Duvoisin Grant was created in his honor in 2002.

Dr. Duvoisin graduated from Columbia University, received his medical degree from New York Medical College, and served in both the US Navy and US Air Force. In the 1960's, he pioneered the use of levodopa to treat PD.

In 1997, Dr. Duvoisin and his team at Rutgers Robert Wood Johnson Medical School collaborated with the National Institutes of Health to publish "*Mutation in the Alpha-Synuclein Gene Identified in Families with Parkinson's Disease*" in the renowned journal, *Science*. The article identified the first of many mutations in the alpha-synuclein gene that cause PD.

From 1979 - 1996, Dr. Duvoisin served as the Medical Director of the APDA Center for Advanced Research at Rutgers Robert Wood Johnson Medical School; a role now held by Dr. Lawrence Golbe. "Roger had many important research achievements, but the most important was the insight, based on careful and systematic observation, that PD is largely genetic in origin despite superficial appearances and his own twin study to the contrary," says Dr. Golbe.

Dr. Duvoisin had the warm, unassuming bedside manner of a country doctor. His powers of discernment were extraordinary. The late Dr. Richard Heikkila, his close friend and collaborator, called him "*the most brilliant diagnostician I have known.*"

Dr. Duvoisin possessed the ideal skills of a clinician and researcher and had the deep respect of everyone in the PD community. We are grateful to him for the transformative impact he had on the course of this disease and know he will be missed by all.

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. I take 150 mg of Sinemet three times a day. In spite of all my exercising, I am beginning to fall again. Would upping my dose make me more likely to have dyskinesia?

A. Dyskinesia can result from too much levodopa in the system, but it's variable from person to person. Your physician should make recommendations that are specific to you. A physical therapy evaluation by a therapist familiar with PD is also important for issues with posture and balance.

Q. Does the body build a tolerance to Sinemet over time? Is it better to delay the start of treatment if symptoms are not that severe?

A. A person does not develop a tolerance to Sinemet. However, a person may develop long-term effects of levodopa, like dyskinesia or motor fluctuations. Some physicians will delay the start of medication or use a milder agent to delay the onset of motor fluctuations. Some individuals' symptoms require that levodopa be started early. It is highly individualized, so it is important to discuss with your physician.

Q. How far does my Parkinson's have to progress to be able to get brain surgery?

A. Generally, Deep Brain Stimulation (DBS) surgery is considered when a person develops motor fluctuations that are not improved by medication adjustments. This could include "wearing off" or "off periods" (when medications don't adequately relieve symptoms), dyskinesia (involuntary movements), or tremors. Researchers continue to study the best time to offer this procedure.

PRESS PROGRAM EXPANDS ACROSS THE U.S.

APDA's new Parkinson's Roadmap for Education and Support Services (PRESS) is an eight week, in-person support series that has expanded to more than twenty sites across the country. This support program features tailored content to address the psychosocial needs of those who have been diagnosed within the last five years. PRESS support groups are facilitated by a trained healthcare professional and provide a structured platform for people to share their experiences, feelings, and strategies for coping with the disease.

To learn more about PRESS or to register for a group near you, contact Emily Ciorciari at eciorciari@apdaparkinson.org or call (800) 223-2732.

PRESS

Parkinson's Roadmap for
Education and
Support Services



What's happening at APDA



Research Video Launch

APDA is thrilled to release a new video that showcases the impact and progress we have made in the research arena since 1961. The video highlights the urgent need to advance science to help stop disease progress and ultimately find a cure. APDA prides itself in funding the brightest talent and attracting researchers to the field who want to make a commitment to building a lifelong career in Parkinson's. To view the video please visit apdaparkinson.org/researchvideo.

Call for Grant Applications

As a part of our initiative to fund the best and brightest scientists in the PD field, we will be accepting applications for research grants up until March 11, 2018. Grants include fellowships, post-doctoral awards, and support for research projects. For more information, please visit apdaparkinson.org/grants.

Watch an Educational Webinar

Our APDA Spotlight webinar series covers a variety of subjects relevant to the PD community, at no cost to the public. Visit apdaparkinson.org/webinar to watch our latest archived webinars, or to tune in for our next live presentation, *Spotlight on Parkinson's Disease: Staying Healthy, Keeping Fit* in March.

A Successful Year of Optimism Walks

In 2017, we hosted 16 inspiring events across the U.S., where local communities came together for a family-friendly, fun-filled day. And next year, we're expanding to 20 Optimism Walks nationwide! Please join us for a Walk near you, or show your support by making a donation. For more details, visit apdaparkinson.org/optimism-walks.