# **AMERICAN PARKINSON DISEASE ASSOCIATION**

# **Annual Report**







Strength in optimism. Hope in progress.

Every day, we provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

MISSION STATEMENT





# From the APDA Chairman of the Board and President & CEO

Dear Friends,

This has been an incredibly exciting year for the American Parkinson Disease Association (APDA) and we're proud to recap some of the successes and progress we've been able to make, thanks largely to your tremendous support and generosity. Whether you read this annual report from cover to cover or you flip through and read a bit here and there, we hope you are able to get a good sense of not only the important work we've been doing, but how we have worked to reach the Parkinson's disease (PD) community in all of its diverse background and need.

Every initiative you will read about in this report was made possible by you; our dedicated group of fierce supporters! Whether you've been supporting APDA for many years, or made your first donation this year — you are our heroes. You make it happen.

As you know, we created a very ambitious 2015-2018 Strategic Plan that included some big changes and called for fast progress. We aimed high, and we've been delivering with your partnership. We can't wait for you to see all you've helped us accomplish in this fight against PD.

Day in and day out, we are able to provide top notch programs and services thanks to our nationwide network of dedicated Chapter staff and volunteers, Information & Referral Center Coordinators and Medical Directors. This year we are also indebted to incredibly talented national advisors and task forces focused on two new initiatives: disparities in access to care, and health and exercise. As a community, APDA is an army with boots on the ground providing that personal touch for those in need every day. PD is not one-size-fits-all, so we continue to focus on ways to provide programs and services that meet a wide range of unique needs for folks from diverse racial, ethnic, and cultural backgrounds, as well as for groups with specific needs such as veterans, early onset PD, and more. These efforts are designed to help people better navigate the disease by learning how to be proactive with their medical team and learning how to successfully advocate for better health outcomes.

We want to help as many people as possible — no matter where they live — and as such we continue to expand our educational offerings through webinars, our

website, printed educational materials, online support and programming, and more. Whatever we can do to broaden our reach and support more people — that's what we're going to do.

One of the best ways we can shape the future for the research community is by funding the smartest, most innovative PD researchers and scientists. Our Scientific Advisory Board works tirelessly to seek out, review and recommend the most exciting and promising research for APDA to fund. In 2017 and we awarded \$1.6 million toward projects that truly have the potential to improve the quality of life for people with PD and may one day end this insidious disease. These projects range from neuroprotection strategies that will slow the progress of the disease, to finding biomarkers which can help measure the activity of the disease, to cutting edge novel ideas and technology such as wearable devices.

You'll see throughout this report a myriad of promising ideas, progress and optimism. We have included stories of inspiration and examples of work well done... but we cannot stop. We won't stop. We are here every day to continue to serve as the most impactful resource for the Parkinson's disease community.

So we forge ahead, and thankfully we do so with you by our side. Read on with pride, friends. Our work is your work. We did this together. And as our partners, we would love to hear your ideas and suggestions — so please reach out to share your thoughts and stories.

Stick with us — we're already making great things happen and we're counting on you to help us achieve more in 2018!

#### With strength in optimism and hope in progress,

Lexus A. Clampers

Patrick McDermott Chairman of the Board

Leslie A. Chambers President & CEO

# 2015-2018 STRATEGIC PLAN ACHIEVEMENTS



### OCTOBER 2015

APDA and the Parkinson's Foundation announce collaboration on **Summer Student Fellowships,** expanding opportunities for talented undergraduates and medical students to gain early exposure to careers in PD.



### **APRIL 2016**

APDA expands offerings for Spanish-speaking audiences, including eight educational brochures and a Spanish webpage.

## SEPTEMBER 2015

APDA launches ambitious three-year strategic plan featuring **five areas of focus.** 



**Summer Student Fellows** 

### **JANUARY 2016**

APDA launches **Spotlight Webinar series** — 11 programs with 5,000+ live participants and 20,000 archived program views (as of August 2017).





**AUGUST 2016** 

APDA funds \$1.6 million in research grants, including the George C. Cotzias Fellowship, three Post-Doctoral Fellowships, seven Research Grants, and eight APDA Centers for Advanced Research. \$1 MILLION FOR 1 MILLION FUNDRAISING CAMPAIGN ACHIEVES GOAL!



## **SEPTEMBER 2016**

APDA staff members and volunteers attend **4<sup>th</sup> World Parkinson Congress** in Portland, OR, educating more than 4,500 attendees and serving as exclusive sponsor of the "WPC Health Professional Networking Session" with 300+ attendees.

## JULY 2016

APDA's *Live with Optimism* Public Service Announcement is selected as **Silver Winner** in the 37<sup>th</sup> Annual Telly Awards.



VIVEK UNNI, MD, PHD

# AUGUST 2016

APDA achieves \$1 million fundraising goal in two-year "\$1 Million for 1 Million" campaign to support the one million Americans living with PD.



# 2015-2018 STRATEGIC PLAN ACHIEVEMENTS



### JANUARY 2017

APDA develops first PD booklet for veterans,

Helping Those Who Serve: Parkinson's Disease Information for the Veterans Community with support from Acadia Pharmaceuticals.



Every day, we provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

### **MARCH 2017**

APDA pilots Parkinson's Roadmap for Education and Support Services (PRESS™), a **psychosocial support group for the newly diagnosed**, in six Chapters across the country.

## JANUARY 2017

APDA partners with the Office of Continuing Professional Education at Rutgers, the State University of New Jersey, to provide an **online program for first responders** to help them recognize the unique symptoms and needs of those with PD.





## FEBRUARY 2017

**APDA launches new brand,** with a new logo and mission statement, and an increased focus on ensuring that every person touched by PD has the resources they need to live the best life possible.



#### Welcome to the new APDA. Strength in Optimism. Hope in Progress.



# **APRIL 2017**

APDA launches the unshakeable spirit **social media campaign,** celebrating the drive, determination, and unrelenting spirit of people impacted by PD.

#### AMERICAN PARKINSON DISEASE ASSOCIATION

#### Smart Patients

SMART PATIENTS PARKINSON'S DISEASE COMMUNITY In partnership with the AMERICAN PARKINSON DISEASE ASSOCIATION

## **AUGUST 2017**

APDA funds more than **\$1.68 million in PD research,** supporting four Post-Doctoral Fellowships, 11 Research Grants, eight APDA Centers for Advanced Research and the second year of the George C. Cotzias Fellowship.

## **MARCH 2017**

APDA launches brand new website with more information, resources and support in a user-friendly format.



## MAY 2017

**APDA partners with Smart Patients** to build an online community for patients and families, extending APDA's ability to help people in any location.



# SUPPORT

# FIRST RESPONDERS IN CAPE COD PARTICIPATE IN SPECIALIZED APDA TRAINING

In 2017, APDA worked with the Rutgers Learning Center to develop a web-based program for police officers, firefighters, and emergency medical service providers. This First Responders Training Program is an important educational program that empowers them to recognize the unique symptoms and needs of those with PD and enables them to provide appropriate care. With a new PD diagnosis every nine minutes, this training is critically important.

Through the APDA Massachusetts Chapter and its local affiliate, the Parkinson's Support Network of Cape Cod, APDA Vice President of Programs and Services, Robin Kornhaber; along with Cathi Thomas, Information and Referral Coordinator at Boston University Medical Center; and Joyce Ginouves, President of the local affiliate, met with first responders on Cape Cod. They presented information about the program and the immediate response was very positive.

There are more than 3,000 individuals with PD living on Cape Cod, and education for first responders is a priority.

The First Responders Training Program is available on the APDA website and also through several state learning sites for certification. APDA's goal is for all states to add this First Responders Training to their program offerings.





Joyce Ginouves, President of the Parkinson's Support Network, Branch of the APDA Massachusetts Chapter, Cathi Thomas, RN, MS, Information & Referral Coordinator at Boston University Medical Center and APDA Vice President of Programs and Services, Robin Komhaber participate in APDA's First Responders Training Program for Cape Cod Emergency Personnel

# PARKINSON'S ROADMAP FOR EDUCATION AND SUPPORT SERVICES (PRESS™)

In the spring of 2017, APDA piloted a support group program entitled Parkinson's Roadmap for Education and Support Services<sup>™</sup>, or PRESS<sup>™</sup>. The unique program is an eight week, in-person support series that was conducted in six states across the country: Arizona, Florida, Massachusetts, Minnesota, Washington, and Wisconsin.

The PRESS support program features tailored content to address the psychosocial needs of those who have been diagnosed with PD within the last five years. 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 PD. PRESS groups have a maximum of 16 members, allowing each participant to share, contribute, and give and receive support in a way that is not possible in larger groups.

"We saw a need for a more specific support program, especially for those who are just starting to navigate the world of Parkinson's," says Leslie Chambers, President & CEO of APDA.

#### SOUTH FLORIDA PILOT SITE

The APDA South Florida Chapter hosted its PRESS support program in Boca Raton.

Rebecca Hahessy, APDA's South Florida Community Development Director, said of the group: "I feel the PRESS program gave local neurologists a more defined reason to refer patients to us. They saw the importance of newly diagnosed people needing extra support and they wanted to be a part of the process. This program is unique to South Florida because no one else is doing a support group program like this. We had great feedback from the pilot group and I look forward to offering it again."

Ivan and Barbara Saiff attended the South Florida PRESS group together. "It was very helpful. We gained a lot of insight from the other people in the group," explains Ivan. "The general support groups are good but they have people in different stages. PRESS was great because we were all in similar situations. It was all brand new to us. Plus we really enjoyed the facilitator."

Ivan first learned of his diagnosis in 2016 when he noticed a difference in his walking and speech. He recognized that the disease was chronic so he would have to find ways to cope. He read a great deal and now focuses his energy on exercise, participating in some form of activity for five to six hours each week. Barbara and Ivan encourage people to support APDA because "the funding goes to so many programs and literature. It's wonderful. We are feeling good with the information we have but without donations these resources might not be here when we need more help."

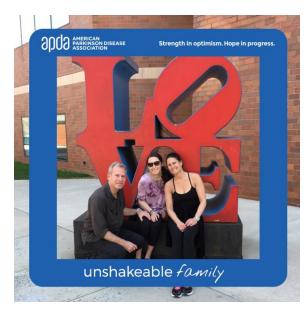
The PRESS program has now formally launched across the country.



Ivan and Barbara Saiff, APDA South Florida Chapter PRESS™ pilot program participants

# SUPPORT

# UNSHAKEABLE SPIRIT SOCIAL MEDIA CAMPAIGN CELEBRATES THE DRIVE, DETERMINATION, AND UNRELENTING SPIRIT OF PEOPLE IMPACTED BY PD



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

In commemoration of Parkinson's Awareness Month in April 2017, APDA launched a new social media campaign entitled *unshakeable spirit*, bringing much-needed attention not only to the disease itself, but to showcase what life is like for those impacted by PD and how to live a full and optimistic life with a PD diagnosis. User-generated content featuring photos and inspiring captions created using APDA's "frame generator" authentically captured and highlighted important moments and attitudes that depicted their unshakeable spirit.

The campaign was conceived by marketing partner teamDigital; a digital and social agency located in the greater New York area. *"As someone who is living with Parkinson's, and as a member of an APDA support group, I am so proud to be supporting the mission of this incredible organization,"* said teamDigital CEO Jeff Butchen. *"APDA is an unshakeable force in the lives of so many, and we at teamDigital are grateful for the opportunity to amplify the work they do nationwide."* 

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. 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 Connecticut 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."* 

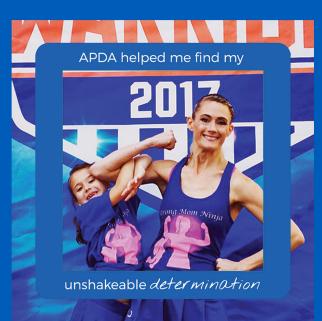
Jeff and his compassionate, very talented staff, fueled by a desire to support Jeff and the fight against PD, offered their unique skillset and expertise — free of charge — to APDA. The result? The inventive, engaging, and powerful *unshakeable spirit* campaign that is helping raise awareness of PD and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













# EDUCATION

# INNOVATIVE ONLINE PD COMMUNITY REACHING ACROSS THE COUNTRY

APDA was proud to kick off a partnership with Smart Patients to create a new online discussion forum for people with PD and their loved ones. Members in this online forum share help, advice and information about treatments, symptoms and side effects.

"We are thrilled with our partnership with Smart Patients to launch this community. This network is designed for people with PD, care partners, and family members," explains Robin Kornhaber, APDA Vice President of Programs and Services. "This innovative opportunity will further a dialogue to nurture the PD community, provide socialization, education, and critical access to information — and will allow us to expand our support across the country."

# **Smart Patients**

An online community where patients and their families learn from each other.

Smart Patients is a forum for people with Parkinson's, their care partners, and families to interact in a safe, supportive environment. Get information from patients who are going through a similar journey with PD. Learn about Parkinson's and community resources to help you proactively live a full life with PD.

> Learn more: www.smartpatients.com/apda



# WEBINAR EDUCATION SERIES

APDA is proud to present the Spotlight Webinar series, featuring topics focused on educating the PD community and helping people impacted by this disease achieve the best quality of life.

These online programs, also accessible via telephone, increase APDA's ability to meet the educational needs of people with PD, their families, and their friends in the comfort of their homes. Downloadable resources, which are available after the live broadcast, are archived on the APDA site at **apdaparkinson.org/webinar**.

### 2017 WEBINARS:

#### Spotlight on Parkinson's Disease: Staying on Your Feet – Balance Matters

Anna DePold Hohler, MD, FAAN and Tami Rork DiAngelis, PT, DPT, GCS Support for this program was provided by Lundbeck.

Spotlight on Addressing Motor and Non-Motor Symptoms: The Changing Landscape David G. Standaert, MD, PhD Support for this program was provided by Joan and Ross Collard and AbbVie.

#### Spotlight on Addressing Movement Function: Coping with On/Off Periods

Lisa M. Shulman, MD Support for this program was provided by Sunovion.

# Spotlight on Living Well with Parkinson's Disease: Living Well Everyday

Lisa Sommers, MA, CCC-SLP and Stacey A. Zawacki, DrPH, RD Support for this program was provided by Acorda and Lundbeck.

#### Spotlight on Parkinson's Disease: Communications and Intimacy

Sheila Silver, MA, DHS, ACS Clinical Sexologist Support for this program was provided by APDA.

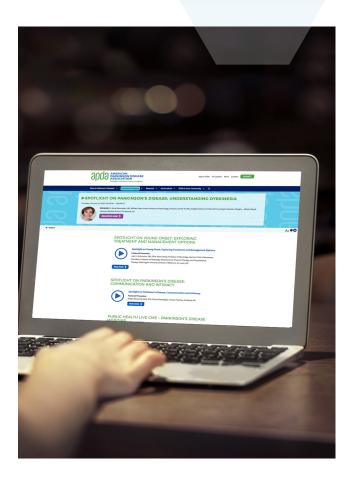
#### Public Health Live – Psychiatric Manifestations of Parkinson's Disease and its Treatment

Guy J. Schwartz, MD

Public Health Live programming was developed in partnership with APDA, the New York State Department of Health and the University at Albany, School of Public Health with CME credits available for healthcare professionals.

#### **Reach of the Webinar Series in 2017**

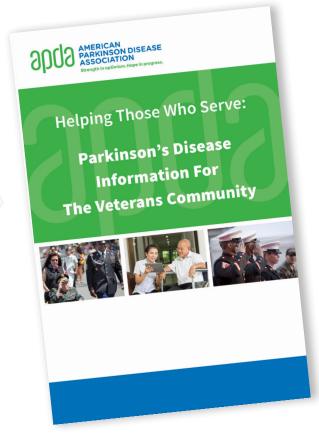
20,000+ online views of the webinar programs 3,500+ live webinar participants (web and phone)



# EDUCATION

# MANUAL FOR VETERANS

In an effort to address the unique issues faced by veterans with PD, APDA published a new guide called *Helping Those Who Serve: Parkinson's Disease Information for the Veterans Community.* This informative manual covers everything from the basics of understanding PD to finding care through the Veterans Health Administration.



APDA is proud to have this opportunity to give care and support for the United States veterans who have selflessly served our country. The manual provides critical information and resources to guide them through the process of this disease, as well as platforms for veterans to connect with one another. Funding for this manual was generously provided by Acadia Pharmaceuticals. You can view the guide at **apdaparkinson.org/VAManual,** or pass it on to a veteran you know who is living with PD.

# APDA GREATER ST. LOUIS CHAPTER OFFERS INNOVATIVE LIVE STREAMING EXERCISE CLASSES

Research shows that exercise is critical for people with PD. It can help improve both motor and non-motor symptoms and may even slow the disease progression. As the largest grassroots organization serving people with PD, APDA is proud to offer access to free and low-cost, evidence-based exercise programming across the country.

The APDA Greater St. Louis Chapter developed innovative exercise classes which they live stream from the Chapter's Resource Center in Chesterfield, Missouri. All instructors in the program receive advanced training in how to understand the unique needs of those impacted by PD and the exercises are designed to address the specific impairments frequently encountered by people with PD.

The live streaming program provides choices in high-quality classes, including chair side exercise, Tai Chi, yoga and interval training. Participants may also choose the levels of challenge, from dynamic standing exercises to less complex seated options. Those who cannot view the live classes can access a library of more than 140 archived classes on the Chapter's website.

The live streaming program gives the participants at home the sense of being in the room and part of the group experience.

The archived classes have been viewed more than 4,000 times. People from all over the world, including France and Australia, have participated in the classes from the comfort of their homes.

Anyone may access both the livestreamed classes and the library of archived past classes at **apdaparkinson.org/greaterstlouis**.

"I can make up missed classes, replay classes to review exercises and supplement my personal routine with exercise ideas taken from the classes. Thank you to the APDA for this innovative service!" — Doug Schroeder, exercise class participant and person with PD





# EDUCATION

# MINNESOTA SYMPOSIUM

This fall brought a significant milestone for the APDA Minnesota Information & Referral Center — their first educational event in Rochester, Minnesota. On October 28, despite the early snowfall the previous day, 100 people with PD and their family members came together at the Wood Lake Meeting Center for the Fall Parkinson's Conference. It was a fantastic day filled with informative, fascinating presentations. APDA convened knowledgeable and caring professionals to share their expertise.

- Dr. Anhar Hassan of the Mayo Clinic presented on the treatment of advanced PD, motor and non-motor symptoms.
- Dr. Rodolfo Savica of the Mayo Clinic presented on risk and protective factors, and survival in PD.
- Beth Millage, DPT, NCS, and Erin Vesey, DPT, of Courage Kenny Rehabilitation Institute and Allina Health, presented on exercise research in PD and the role of physical therapy.

"The speakers addressed a great variety of subjects and answered every question. I loved it. It was very informative."

- Attendee of the Minnesota Symposium





The American Parkinson's

# Saturday, Oct. 28, 2017

9 a.m. to 1 p.m.

Free surface parking Center | 210 Woodlake Dr. Rochester, MN 55

#### resentatio

Treatment of Advanced Parkinson's Disease, Motor & Non-Motor Symptoms - Dr. Anhar Hassan, Mayo Clinic Risk & Protective Factors, and Survival in Parkinson's Disease - Dr. Rodolfo Savica, Mayo Clinic

How Can I Stay Active with PD? Updates on Exercise Research in PD and the Role of Physical Therapy – Beth Millage, DPT, NCS and Erin Vesey, DPT, Courage Kenny Rehabilitation Institute, part of Allina Health

Question & Answer Panel featuring speakers Dr. Rodolfo Savica, Beth Millage, DPT, and Erin Vesey, DPT This conference is free to attend and lunch will be provided. This program offers 4 contact hours of continuing education.

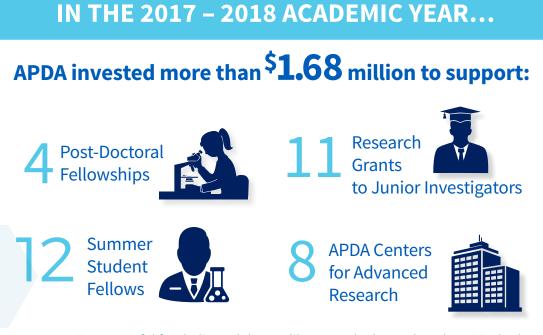
For more information or to register, visit fallparkinsonsconference.eventbrite.com, or email Anushka at anushka.mohideen@allina.com. Questions? Call Anushka at 651-241-8297.

Allina Health 🐝



# RESEARCH

Since its founding in 1961, APDA has contributed more than \$46 million to support scientific research designed to unlock the mysteries of Parkinson's and ultimately put an end to this disease. With the collective efforts of the brightest students, scientists, and researchers, APDA is working tirelessly to find a cure.

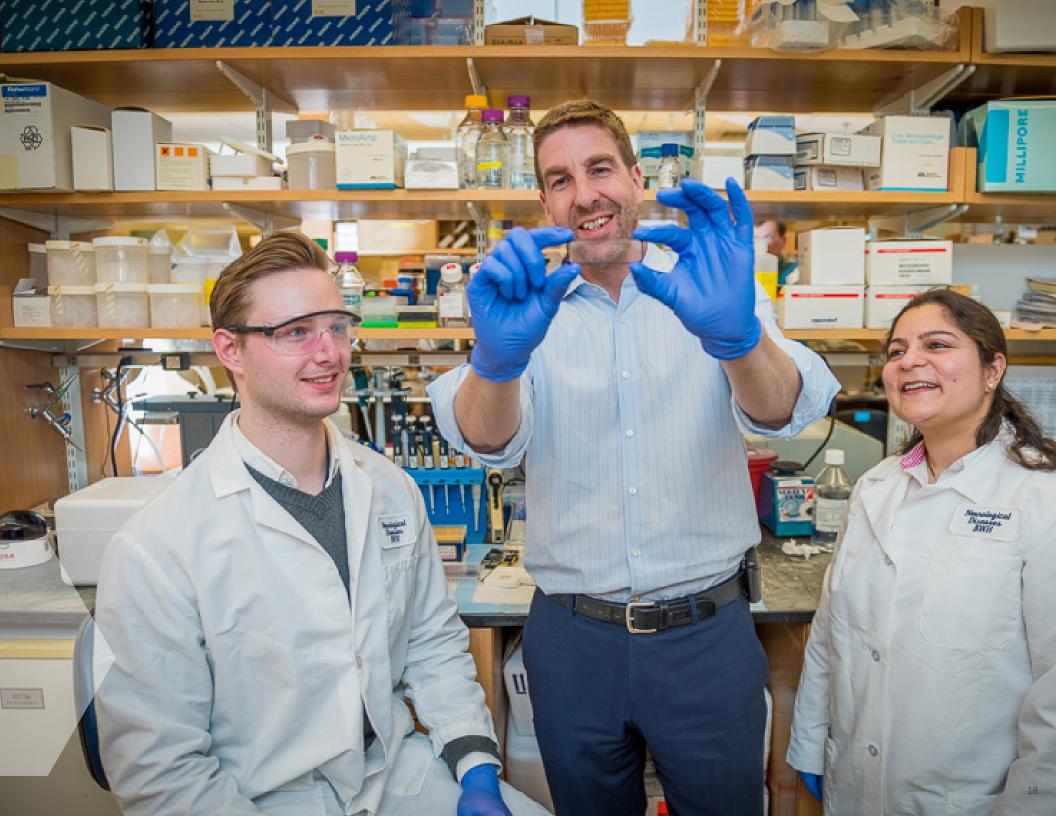


APDA is so grateful for dedicated donors like you, who have played a critical role in funding cutting-edge research projects.

# APDA GRANT PROCESS

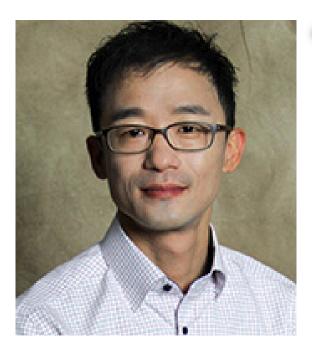
In order to ensure that APDA is investing in the best science, grants are awarded through a competitive application process. Each grant is reviewed by APDA's Scientific Advisory Board (SAB) — a group comprised of scientists with a wide array of backgrounds and expertise in all areas relevant to PD research.

The SAB focuses on funding scientists who are at the start of their PD research career, and seeks to attract the brightest minds. The 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.



# RESEARCH

# DR. BEOM-CHAN LEE



Dr. Beom-Chan Lee, assistant professor at the University of Houston Department of Health and Human Performance, is creating the Smarter Balance System to help with in-home balance training.



Postural instability, a cardinal symptom of PD, can result in loss of balance and increased risk of falling, thus reducing independence in daily activities. Existing dopamine replacement therapies do not treat postural instability effectively, but Dr. Lee and his team have demonstrated in laboratory settings that balance training assisted with biofeedback technologies decreased body sway and increased a range of motion for people with PD. However, lab-based biofeedback technologies are impractical for use in the home due to size, weight, calibration procedures, cost, and fragility. They also lack user-friendly interfaces and simplified displays.

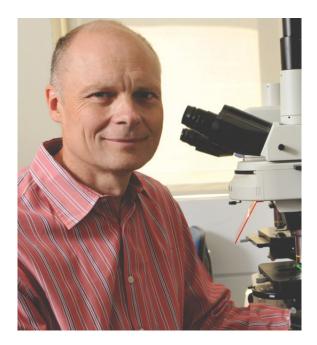
APDA's initial funding of Dr. Lee's work through a Research Grant in 2016-2017 was instrumental in the development of a small, lightweight, easy-to-use, smartphone-based system called the Smarter Balance System (SBS).

"Aided by a research grant from APDA, we took a major step toward developing smartphone-based, wearable technology that can be easily and readily used in a home environment to improve postural instability for people with PD," Dr. Lee said.

Improvements in balance that are retained for weeks or even months after extended balance rehabilitation training with the SBS will improve quality of life, giving people with PD more confidence in performing daily tasks. The user-friendly, wearable characteristics of the smartphone-based technology will reduce the need for family members and care partners to assist during balance rehabilitation training.

APDA funded a second study being conducted by Dr. Lee and his team to assess the impact on long-term rehabilitative training for people with PD who receive in-home balance exercises with assistive guidance via SBS. They will quantitatively and qualitatively analyze the carry-over effects of long-term rehabilitative training with SBS on balance performance, daily physical activities, and confidence in less fear of falling.

## **DR. ANDREAS KOTTMANN**



Dr. Andreas Kottmann is an associate professor at the CUNY School of Medicine at the City College of New York in New York City. He has been awarded two APDA research grants for his work related to Levodopa-induced dyskinesia (LID), which is characterized by fragmented or jerking movement of the limbs or torso brought on by Levodopa. In the first study funded by APDA in 2015-2016, Dr. Kottmann and his team discovered that when neurons degenerate in PD, they secrete a protein called "Smoothened," which reduces the severity of LID.

"Discussion with and observance of people with LID helped to guide our thinking and reasoning," says Dr. Kottmann. These discussions sparked a thought for the team, "Could this finding on Smoothened have implications for patients coping with LID?"

Successful findings in this study were instrumental in winning funding from the National Institute of Neurological Disease and Stroke in July of 2016.

Dr. Kottmann once again received APDA funding in 2017-2018 with a project entitled *Validation* of the G-Protein Coupled Receptor Smoothened as a Target for Ameliorating L- Dopa Induced Dyskinesia.

Dopamine neurons communicate not only by dopamine, but also by other secreted cellsignaling molecules with other neurons. His team found that the experimental, genetic ablation of one of these auxiliary signaling factors, sonic hedgehog or Shh, from DA neurons results in a mouse line with progressive cellular, neurochemical and motor behavioral deficits that are reminiscent of PD. Interestingly, this mouse line exhibits dyskinesia upon chronic Levodopa dosing. Conversely, they found that compounds that act as agonists of the Shh co-receptor Smoothened can ameliorate the formation and display LID in mice.

Dr. Kottmann has high hopes that these findings will prove successful when extended to human trials, so that patients can be relieved of dyskinesia. "There is no doubt that inhibition of LID will improve the quality of life for people with Parkinson's disease," he says.

# RESEARCH

# SCIENTIFIC ADVISORY BOARD (AS OF DECEMBER 2017)



#### APDA Scientific Advisory Board:

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

#### Chairman

#### David G. Standaert, MD, PhD

John N. Whitaker Professor and Chair of Neurology University of Alabama at Birmingham, School of Medicine

#### Members

#### Marie-Francoise Chesselet, MD, PhD

Charles H. Markham Professor of Neurology Emerita David Geffen School of Medicine at UCLA

Mahlon R. DeLong, MD Timmie Professor of Neurology Emory University School of Medicine

**Dennis W. Dickson, MD** Professor of Laboratory Medicine & Pathology Mayo Clinic, Jacksonville, Florida

J. Timothy Greenamyre, MD, PhD Love Family Professor and Vice Chair of Neurology University of Pittsburgh Medical Center

#### Un Jung Kang, MD

H. Houston Merritt Professor of Neurology Columbia University College of Physicians and Surgeons

#### Laura Marsh, MD

Professor of Psychiatry, Michael E. DeBakey VA Medical Center

#### Mary Maral Mouradian, MD

William Dow Lovett Professor of Neurology Rutgers Robert Wood Johnson Medical School

**Richard Myers, PhD** 

Director, Genome Science Institute Professor, Department of Neurology Boston University School of Medicine

#### Joel S. Perlmutter, MD

Elliot Stein Family Professor of Neurology Professor of Radiology, Neurobiology, Physical Therapy & Occupational Therapy Washington University School of Medicine

Marie Hélène Saint-Hilaire, MD, FRCP (C) Professor of Neurology Boston University School of Medicine

Clemens R. Scherzer, MD

Associate Professor of Neurology Harvard Medical School

#### Evan Yale Snyder, MD, PhD

Director, Stem Cell & Regeneration Program The Burnham Institute



**Boston University School of Medicine** – Boston, MA



**Emory University School of Medicine** – Atlanta, GA



**Washington University** School of Medicine – St. Louis, MO

# **CENTERS FOR ADVANCED** RESEARCH

APDA's Centers for Advanced Research support research trainees, fellowship programs, early-stage discovery and later-stage clinical translation. The Centers facilitate investigative research into the causes, treatments, and ultimately a cure for PD.



**Rutgers Robert Wood** Johnson School of Medicine - New Brunswick, NJ



**University of Virginia Health System** – Charlottesville, VA

University of Alabama at Birmingham School of Medicine - Birmingham, AL



**University of Pittsburgh Medical Center** – Pittsburgh, PA



**David Geffen School** of Medicine at UCLA – Los Angeles, CA

# Strength in optimism. Hope in progress.

# FUNDRAISING



SSOCIATION

# APDA OPTIMISM WALK GROWING AND LOOKING GREAT IN 2017!

For the 2017 season, the Optimism Walk stepped out with a whole new look. As part of the larger organization-wide rebranding effort, APDA unveiled a brand new Optimism Walk logo that complements the energy and revitalization of the overall APDA rebrand. The new logo was incorporated into all facets of the Optimism Walk experience, from the moment a participant registered online until they crossed the finish line at the Walk itself.

And the logo wasn't the only new thing in 2017 — APDA added three new Optimism Walks this year — in Southern California, St. Louis, MO and Broken Arrow, OK! Special thanks and congratulations to the strong teams of staff and volunteers who were on the ground leading these new efforts.

As APDA's signature fundraising event, it is essential for the program to grow and succeed, bringing these inspiring, family-friendly events to additional communities across the country. The more funds raised at each Optimism Walk, the more people APDA helps with local programs, services and educational support, so their success is critical to APDA's work.

Special thanks to pharmaceutical companies Lundbeck, AbbVie, and Sunovion for supporting the 2017 Optimism Walk event series.



Superstar volunteers in Southern California



Walking strong in St. Louis



Coming around the bend in Oklahoma

Keep an eye on the 2018 Optimism Walk calendar to see even more Walks added to the schedule! Find one near you and join APDA!

# APDA NORTHWEST CHAPTER MAGIC OF HOPE GALA

The 15<sup>th</sup> annual Magic of Hope Auction & Gala was held in April in Seattle. More than 400 guests came together to celebrate the PD community and bid on exciting auction items. Long-time supporters John and Suzie Schofield were honored for their energy and unwavering commitment to help countless people impacted by PD. Their eight-year-old son Buckley stole the show during the "Fund a Need" portion, when he helped raise over \$185,000, bringing the evening's grand total to \$410,000. It was truly a magical evening!





Magic of Hope Honorees Suzie, John and Buckley Schofield



#### Magic of Hope Gala:

APDA Northwest Chapter Magic of Hope Gala 2017(L-R) David Espinosa-Hall, KING5 TV News Anchor, Gala emcee; Jean Allenbach, Northwest Chapter Executive Director; Leslie A. Chambers, APDA President & CEO

# FUNDRAISING

# **GEORGIA GOLF OUTING**

The APDA Georgia Chapter held another successful golf tournament on June 5, 2017, at one of Atlanta's most recognized golf courses, Dunwoody Country Club. 110 golfers and volunteers were on hand for the day, which included an awards dinner and silent auction that raised approximately \$48,000.



Affectionately known as the "Driving Parkinson's Away" Golf Tournament, this annual event has been hosted by the APDA Georgia Chapter since 2002. Participants enjoy a day of camaraderie, a round of golf at one of Atlanta's premier country clubs, and the opportunity to raise funds for Parkinson's disease research, public awareness and support programs. The event was started as a tribute to Georgia resident Bill Pender, who lived with PD for 24 years and was the driving force behind the tournament. Mr. Pender passed away in November 2017. The Pender Cup will be awarded in 2018 in loving memory of his dedication and commitment to serving those with PD.

#### **GA Golf Outing:**

APDA Georgia Chapter Board, Golf Committee Members and Staff (L-R): Deb Papenhagen, Anne Maloney, Katie Beasley Beshara, Melissa LeBoeuf, Elliot Coplin, Eric Burkard, Barbara Mooney, Ken Alfiero, Paul Demick

## LEADERSHIP (AS OF DECEMBER 31, 2017)

#### **EXECUTIVE COMMITTEE**

*Chairman:* Patrick McDermott

*1st Vice Chair:* Thomas K. Penett, Esq.

*2nd Vice Chair:* Elliot J. Shapiro, PE

*Secretary:* Sally Ann Esposito Browne

*Treasurer:* Elena Imperato

Joseph G. Conte Mario J. Esposito, Jr.

#### DIRECTORS

Elizabeth Braun, RN David J. Butler Athol Cochrane George A. Esposito Jr., Esq. Lisa Esposito, DVM Michael Esposito Donna J.C. Fanelli Marvin Henick Michael Melnicke Joel A. Miele Jr. Michael Pietrangelo, Esq. David G. Standaert, MD, PhD

HONORARY PAST CHAIRMEN OF THE BOARD OF DIRECTORS

Vincent N. Gattullo Fred Greene

#### **EMERITUS MEMBERS**

Donna Marie Foti The Hon. John Fusco Paul Gazzara, MD Michael Halkias John. Z. Marangos, Esq. Frank Petruzzi Robert Pierrello Dorothy Reimers Scott Schefrin Jay A. Springer, Esq. Martin Tuchman Jerry Wells, Esq.

#### SENIOR STAFF

*President & CEO:* Leslie A. Chambers

*Vice President of Programs & Services:* Robin Kornhaber, MSW

*Vice President of Development & Marketing:* Stephanie Paul

Vice President of Chapter Development & Field Operations: Penny Westberry, MSW

# **IN MEMORIAM**

Vincent Gattullo, APDA's former Chairman and President and CEO, who passionately served the organization and the PD community for more than thirty years, passed away on September 12, 2017.



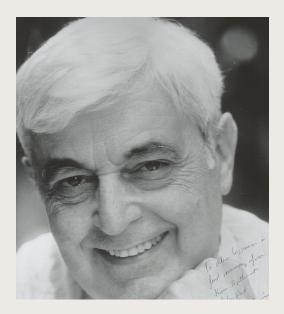
VINCENT GATTULLO 1931 – 2017

Mr. Gattullo began his service to APDA in 1986, first as a member of the Board of Directors, and then as President and CEO and Chairman of the Board from 2001-2008. He remained on the Executive Committee until January 2016, when he resigned and was named Honorary Chairman of the Board of Directors. Mr. Gattullo was an instrumental leader who helped APDA raise millions of dollars to fund much-needed research, education, and support to assist those impacted by PD throughout the United States.

A biologist and experienced educational leader, Mr. Gattullo served as director of the Staten Island Zoological Society for 25 years after his retirement from the New York City Board of Education. He was also an assistant professor of biology for three years at the New York City University College of Staten Island. In addition to being an author and editor for several professional publications, he developed science programs that received six National Science Foundation grants.

Mr. Gattullo will be missed by all and APDA is indebted to him for his commitment and service.

Dr. Roger C. Duvoisin, a neurologist who played a leading role in breakthroughs in treating PD and discovering genetic roots of the disorder, passed away on October 5, 2017.



ROGER C. DUVOISIN, MD 1927 – 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 was a pioneer in developing the use of the Levodopa to treat PD in the 1960's. In 1997, he and his team of clinicians and researchers at Rutgers Robert Wood Johnson Medical School, in collaboration with scientists at the National Institutes of Health (NIH), published *"Mutation in the Alpha-Synuclein Gene Identified in Families with Parkinson's Disease"* in the renowned journal, *Science*. In it, they identified the first of many mutations in the alpha-synuclein gene that cause PD.

Dr. Duvoisin graduated from Columbia University and received his medical degree from New York Medical College. He served in both the US Navy and US Air Force.

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."* 

From 1979 to 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" said Dr. Golbe.

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

# **FINANCIALS**

APDA is keenly aware of the many choices donors have in how they direct their charitable giving. At the core of APDA's fiduciary responsibility is the commitment to be stewards of donors' trust, and ensure that administrative and fundraising costs are kept to a minimum.

Since 1961, APDA has invested more than \$170 million to fund research, provide patient services and education, and to elevate public awareness.

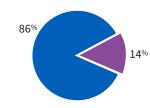
The 2017 financial highlights follow. The entire audited financial statement and most recent IRS Form 990 are available at apdaparkinson.org.

The American Parkinson Disease Association is a 501(c)(3) nonprofit organization.

# STATEMENTS OF FINANCIAL POSITION

	August 31,		
	2017	2016	
ASSETS			
Cash and equivalents Bequests receivable, net Contributions receivable Investments Investments held for charitable gift annuities Prepaid expenses and other assets Property and equipment, net	\$ 7,681,187 405,733 57,298 1,730,847 50,155 359,156 2,555,722	\$ 6,657,001 307,448 - 1,370,958 65,576 360,973 2,585,127	
Total Assets	\$ 12,840,098	\$ 11,347,083 	
LIABILITIES AND NET ASSETS			
LIABILITIES:			
Accounts payable and accrued expenses Deferred revenue Grants payable, net Charitable gift annuities payable	\$ 406,621 188,626 1,109,386 47,274	\$ 383,276 109,264 1,304,926 49,376	
Total Liabilities	1,751,907	1,846,842	
COMMITMENTS			
NET ASSETS:			
Unrestricted net assets Temporarily restricted net assets Permanently restricted net assets	8,707,244 2,208,003 172,944	7,097,138 2,230,159 172,944	
Total Net Assets	11,088,191	9,500,241	
Total Liabilities and Net Assets	\$ 12,840,098	\$ 11,347,083	

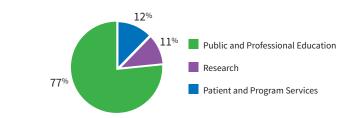
#### Fiscal Year 2017 Expense Composition



Program and Services Administrative and Fundraising

While it varies slightly from year to year, Fiscal Year 2017 Audited Financial Statement shows 86% of expense went toward APDA's mission while 14% went to Fundraising and Administration.

#### Fiscal Year 2017 Program Expense Composition



August 21

# STATEMENTS OF ACTIVITIES

WITH COMPARATIVE TOTALS FOR 2016

WITH COMPARATIVE TOTALS FOR 2016				August 31,		
		Temporarily	Permanently	То	Total	
	Unrestricted	Restricted	Restricted	2017	2016	
SUPPORT AND REVENUES:						
Contributions	\$ 4,534,662	\$ 972,462	\$ -	\$ 5,507,124	\$ 4,860,411	
Legacies, bequests and estates	2,812,236	998,360	-	3,810,596	2,236,460	
Special events	1,955,758	398,427	-	2,354,185	1,773,483	
Investment return	316,836	-	-	316,836	87,009	
Contributed services	10,653,917	-	-	10,653,917	11,849,117	
Other revenue	47,292			47,292	102,053	
	20,320,701	2,369,249		22,689,950	20,908,533	
NET ASSETS RELEASED						
FROM RESTRICTIONS	2,391,405	(2,391,405)		-		
Total support and revenues	22,712,106	(22,156)	<u>-</u>	22,689,950	20,908,533	
EXPENSES:						
Program Services:						
Patient and program services	2,122,083	-	-	2,122,083	2,120,561	
Research	1,974,304	-	-	1,974,304	1,585,732	
Public and professional education	14,034,024	-	-	14,034,024	14,359,757	
Total program services	18,130,411			18,130,411	18,066,050	
Supporting Services:						
Management and general	789,046	-	-	789,046	746,861	
Fundraising	2,182,543	-	-	2,182,543	2,121,943	
Total supporting services	2,971,589			2,971,589	2,868,804	
Total expenses	21,102,000	<u> </u>		21,102,000	20,934,854	
CHANGE IN NET ASSETS	1,610,106	(22,156)	-	1,587,950	(26,321)	
NET ASSETS, BEGINNING OF YEAR	7,097,138	2,230,159	172,944	9,500,241	9,526,562	
NET ASSETS, END OF YEAR	\$ 8,707,244	\$ 2,208,003	\$ 172,944 	\$ 11,088,191	\$   9,500,241	

# THANK YOU!

Our work is made possible by friends and supporters like you.

Thank you for all you do!



ou engli in optimisti. Hope in progress

#### **American Parkinson Disease Association**

Parkinson Plaza • 135 Parkinson Avenue • Staten Island, NY 10305-1425 (800) 223-2732 • www.apdaparkinson.org • E-mail: apda@apdaparkinson.org