Look Closer

AMERICAN PARKINSON DISEASE ASSOCIATION

2018 Annual Report

apda AMERICAN PARKINSON DISEASE ASSOCIATION

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.

From the APDA Chairman of the Board and President & CEO

Dear Friends,

Before we go any further, thank you. Thank you for being by our side as we work tirelessly every day to provide the support, education, and research that will help everyone impacted by Parkinson's disease (PD) live life to the fullest.

We are always so eager to share our success and progress with you, because you make it all possible. We hope you'll take some time to review this year's annual report because whether you've made one donation to the American Parkinson Disease Association (APDA) or 100 donations, or given a gift of your time and effort, you've played a part in the exciting and important work that we do every day. Every grant that we fund, every educational publication we offer, every support group we host is possible because of your support.

It's been a busy and very productive year, largely driven by our 2015–2018 strategic plan. A solid strategic plan is essential to keep us focused and make sure our work is as impactful as possible. As we close out the end of our fiscal year and the end of the three-year strategic plan, we are pleased to be able to share our progress in achieving and exceeding the goals we set for ourselves. This report highlights some of the key achievements, such as the launch of our *Look Closer* public service announcement (PSA) that encourages people to look beyond the disease and see the amazing people who are living with PD every day; and like the $1.7 million in grant funding we awarded to some of the brightest minds in PD research for innovative exploration into ideas like new biomarkers of PD, the scientific basis for gender differences in PD, the differences in PD among people of varying ethnicities, and so much more.

Just because we set some ambitious goals and reached them, doesn't mean we're slowing down. Quite the opposite. We are ramping up and forging ahead on our next three-year plan, which incorporates even bigger and more challenging goals. We know we can do this — especially if we have you by our side.

These are your accomplishments as much as ours. We hope you are as proud to read about them as we are to share them.

With strength in optimism and hope in progress,

Patrick F. McDermott

Patrick McDermott
Chairman of the Board

Leslie A. Chambers

Leslie A. Chambers
President & CEO

2015–2018 STRATEGIC PLAN HIGHLIGHTS

1. Deliver Innovative Programs & Services

2. Support & Expand Parkinson's Disease Research

3. Increase Public Awareness of Parkinson's Disease & APDA

4. Increase Revenue to Support Mission Delivery

2018 marked the end of APDA's three-year strategic plan that served as a compass for all that we did every day. This strategic plan — the organization's first ever — guided our every action as we worked tirelessly to help everyone impacted by PD live life to the fullest. We are happy to report that we achieved, and in many cases exceeded, our goals in every facet of the plan. The 2019–2021 strategic plan is underway and will continue to keep us focused on what matters most — helping the PD community every step of the way.

1. DELIVER INNOVATIVE PROGRAMS AND SERVICES

Provide innovative signature programs and services to all impacted by PD across the disease continuum and increase annual program participation.

apda AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

PRESS

Parkinson's Roadmap for Education and Support Services

This program is made possible by generous support from Lundbeck.

Launched PRESS ™ (Parkinson's Roadmap for Education and Support)

Each PRESS program is a consecutive eight-week small group meeting that provides the opportunity to share and learn from others who are newly coping with a PD diagnosis. A credentialed psychosocial healthcare professional facilitates each program. We piloted the program in 2017 and formally launched it nationwide in 2018.

Program impact:

96% felt the program succeeded in meeting its **goals**

84% experienced an improvement in how they address the **day-to-day challenges** they identified at the beginning of the program

95% said as a result of the program, they'd be interested in attending additional **APDA meetings**

First Responder Training Launched

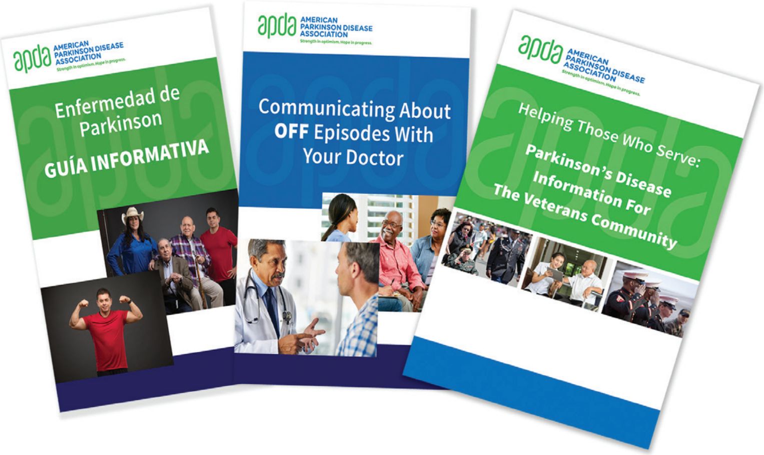
In conjuction with our New Jersey Chapter and in partnership with the Office of Continuing Professional Education at Rutgers, The State University of New Jersey, we created a web-based, user-friendly program for police officers, firefighters and emergency medical service providers. This program helps them recognize the unique symptoms and needs of those with PD and enables them to provide the best and most appropriate care.

Four states have added the training program to their learning center sites: New Jersey, Pennsylvania, New Hampshire and South Carolina.

5,443 people have completed the **online course**

Publications Updated and Translated

All APDA educational materials have been revised and reprinted with our new branding, featuring additional resources that are continuously developed to meet the needs of the PD community. Most publications are now available in English and Spanish, and a Spanish webpage was launched in 2017.



apda AMERICAN PARKINSON DISEASE ASSOCIATION
Enfermedad de Parkinson
GUÍA INFORMATIVA

apda AMERICAN PARKINSON DISEASE ASSOCIATION
Communicating About OFF Episodes With Your Doctor

apda AMERICAN PARKINSON DISEASE ASSOCIATION
Helping Those Who Serve:
Parkinson's Disease Information For The Veterans Community

Webinars: September 2015–August 2018

In 2015, APDA successfully launched the Spotlight Webinar series, featuring programs focused on educating the PD community and providing the best quality of life for those impacted by this disease. The Spotlight series is accessed live by participants nationwide and across the world. All webinars are archived on the APDA website to view any time, as well as in podcast format.


apda AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

Register for our upcoming programs by clicking on the program links below:

Spotlight on Parkinson's Disease: Managing Your Symptoms

Delivered 16 **webinars**

More than 7,200 **people** participated in the **live programming**

More than 52,000 **post-program downloads**

Nearly 5,000 **podcast downloads**

Focus Groups:

APDA hosted four focus groups with Latinos, Hispanics and African Americans, in order to better understand the experiences of people impacted by PD in these populations. These groups looked at issues of awareness, diagnosis, treatment and support services. They also identified barriers to diagnosis and treatment, as well as explored unmet needs. Results will help shape community outreach and service solutions.

2. SUPPORT AND EXPAND PD RESEARCH

Increase APDA research funding allocation by at least 25% by 2018 and advance research efforts in PD through continued advocacy, collaboration and funding of the most promising clinicians and scientists.

Research Grants

From 2015–2018 APDA awarded more than $6.34 **million via 79 grants**

Research Video

In 2017, APDA released a research 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 that can identify novel therapies, help slow the disease's progression and, ultimately, find a cure. APDA is proud to fund the brightest talent and attract researchers to the field who want to make a lifelong commitment to a career in PD research.

3. INCREASE PUBLIC AWARENESS OF PD AND APDA

Increase the public’s awareness of PD as a major health issue and of APDA as a leader in the PD arena by broadening the reach of APDA messaging by at least 25% by 2018.

New Brand

In 2017, APDA launched a 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.

Raising Awareness

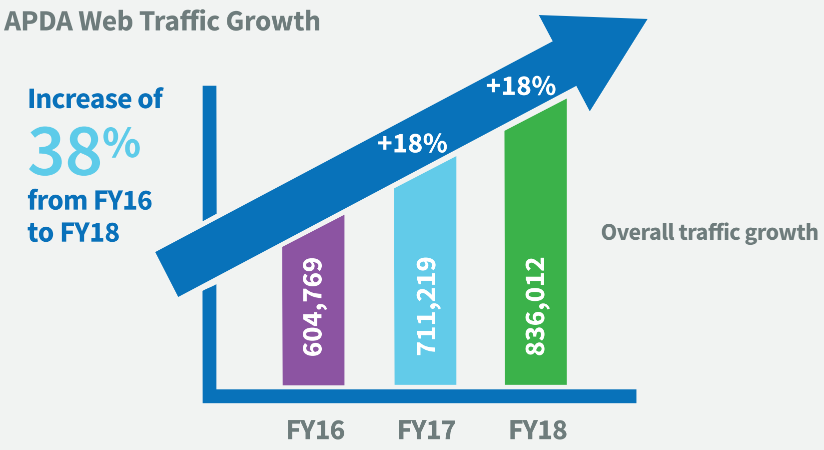
As a follow-up to the successful *Live with Optimism* public service announcement (PSA) that ran nationwide from 2015–2018, APDA launched a new *Look Closer* PSA campaign that encouraged viewers to look closer at people with PD.

Featured nationwide on television (in English and Spanish) and in a social media campaign, *Look Closer* has expanded the public’s understanding of the disease and gives hope to those already impacted by PD.

Live with Optimism
campaign ran from 2015–2018

Look Closer
PSA campaigns in English and Spanish launched April 2018

PSA’s
shown on television nationwide an average of **30,000 times per year**


APDA Web Traffic Growth

4. INCREASE REVENUE TO SUPPORT MISSION DELIVERY

Expand mission delivery and broaden organizational impact by 25% in all fundraising campaigns and initiatives combined by 2018.

- From 2015–2016, APDA successfully achieved nationwide ***$1 Million for 1 Million*** fundraising initiative, raising **$1,000,000 in new funding** to support the approximately one million people in the U.S. living with PD — these critical funds have helped provide more services to those touched by PD
- Grew APDA ***Optimism Walk*** Series contributions by **129%** and expanded the number of *Optimism Walks* from **13 annual events to 19**
- Grew national ***Optimism Walk*** corporate sponsorship by **120% from 2015–2018**
- Grew fundraising by **21%** through **19 chapters** across the country

Optimism Walks take place across the country.

A CLOSER LOOK BLOG

A CLOSER LOOK WITH DR. REBECCA GILBERT

A Closer Look aims to address both timely and timeless topics related to Parkinson's disease (PD). In addition, we will focus on practical, take-home tips that can be gleaned from the information discussed. We also want to address topics that are of interest to you, our readers, people impacted by PD who are striving to live each day to the fullest. We encourage you to subscribe to the blog and suggest blog topics.

Dr. Rebecca Gilbert, *APDA Vice President and Chief Scientific Officer*

ASK THE RESEARCHER: DR. AASEF SHAIKH

Ask the Researcher: Dr. Aasef Shaikh

THE NEWS YOU NEED

In today's hyper-connected world, you can find an almost infinite amount of information about PD. It can be hard to know what to read, what to believe and, most importantly, what changes someone with Parkinson's should (or shouldn't) implement in their life.

We designed *A Closer Look* to help identify the most important and useful information. Penned by APDA's Chief Scientific Officer, Dr. Rebecca Gilbert, the blog addresses both timely and timeless topics related to PD and explains them in a way that's easy to understand. Each entry highlights practical tips and takeaways to help people determine how to best apply the information to their PD journey.

We've already covered a steady flow of exciting and thought-provoking topics including:

- Marijuana and PD
- Understanding Stem Cell Therapy
- The Promise of Telemedicine
- Improving Quality of Life Through Exercise
- And so much more!

There are many great topics still to be covered and readers can send in suggestions for future blog topics.

LOOK CLOSER PSA LAUNCH

TITLE
APDA Public Service Awareness Campaign
DIR
Maker, M
DP
Patterson, R

DATE
07 Feb 2018
TIME
14:34
FPS
24
CAMERA
A

Scene
LOOK CLOSER

SLATE	ROLL	SCENE	TAKE
A1	1	3	4

NOTES

INT DAY MOS
EXT NIGHT SYNC

Raising awareness of PD is essential — not only to raise more funds for programs and research, but also to help those living with the disease know that APDA is here for them every step of the way. Awareness is also vital to help those with PD feel understood and accepted by others. With this in mind, APDA created a brand-new PSA this year that encourages viewers to look closer at the people behind the diagnosis of PD. Featured nationwide on television (in English and Spanish) and in a social media campaign, *Look Closer* aims to expand the public's understanding of the disease and give hope to those already impacted by PD.

"The eight people featured in the PSA are just a small sampling of the amazing people we meet every day who are tackling their PD journey with optimism and resolve," states Leslie A. Chambers, President and CEO of APDA. "From extreme athletes diagnosed in their 30s, to a bridge-playing senior who's been living with PD for seven years, to a rodeo champion diagnosed just over a year ago, we feel that it's so important to show the public that people with PD are living full and fruitful lives, despite their diagnosis. They may tremor, they may struggle, but they approach each day with hope and determination, and they get out there and do the things that make them happy. That is a side of PD that people need to see."

Digital access of the PSA through APDA website, Facebook and Twitter resulted in nearly **10,000 views** through August 2018. Our behind-the-scenes cast videos have more than **14,000 views!**

PATIENT STORIES

With every PD diagnosis comes many stories. The story of the person with the disease and their journey, as well as the story of the care partner who is instrumental in that journey and also experiences a journey of their own along the way. The stories of the friends, family and coworkers who also play a role. There is no shortage of stories and experiences in the world of PD, and each story is very different because no two cases of PD are the same. Our new *Look Closer* PSA urges people to take a moment to learn more about someone beyond their diagnosis and beyond their tremor or other outward symptoms. There are so many stories of inspiration, hope, challenge and support.

We'd like to introduce you to two of our PSA cast members so you can look closer and see them for the amazing people they are. You can learn more about all of the PSA cast in their behind-the-scenes videos on **www.apdaparkinson.org/lookcloser**.

RICHARD

"I have Parkinson's, it doesn't have me." This former actor wants people to look at him and see a healthy person with PD. Diagnosed in 2015, Richard isn't letting his PD keep him from living a full life. His "use it or lose it" attitude keeps him active in the gym, in boxing class and on the dance floor. He also sings and works part-time. With the support of his loving wife, Doris, he is confident and considers himself the picture of health with an "I can do it" mentality. He is thankful that APDA opened the door to so many wonderful things for him.

VICTORIA

"My community is unshakeable." Victoria's experiences as an actress and professional dancer have helped her in many ways. She believes that her dancing and flexibility have helped delay some PD symptoms. Diagnosed at the young age of 38, this mother of two doesn't complain about her PD. Although she admits there are days that are more challenging, she knows that PD is a journey and is grateful for moments of joy — dancing, acting, spending time with friends. Her PD has helped her learn how to take care of herself, and she is grateful to APDA for helping with any information she needs or questions she needs answered. She states, "I know APDA wants to see me live well and be well every day."

PATIENT SERVICES UPDATE

2017 WEST COAST FORUM

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 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 and treatments, as well as 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 and 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 — and became a two-time contestant on TV's *American Ninja Warrior!* An incredible role model to her young daughter, her fellow people with PD and all of us, Allison, along with her story and positive attitude, was the perfect close to an incredible weekend.

The event was made possible thanks to support from AbbVie, Acadia Pharmaceuticals, Inc. and Sunovion Pharmaceuticals.


"Current Research in Parkinson's — Moving The Needle" panel discussion featuring (L to R) Dr. Natalie Diaz, Dr. Ehco Tan, Dr. Beate Ritz and Leslie Chambers.


Guests enjoying themselves at the dinner dance.

WEBINAR EDUCATION SERIES

APDA proudly continued the Spotlight Webinar series with five new programs reaching more than 14,500 people impacted by PD. These enlightening webinars provided important information that will help people with PD better navigate the disease and live life to the fullest. Programs are presented by some of the top experts in the field, and those who participate live have the opportunity to ask the presenters questions. People can participate in the comfort of their own homes, offices or wherever they have access to a computer or phone — making reliable, current information accessible to more and more people, wherever they are.

Downloadable resources and the archived webinars are all available on the APDA website at **www.apdaparkinson.org/webinar/**.

2018 WEBINARS

Spotlight on Parkinson's Disease: The ABCs of DBS
Speaker, Jill L. Ostrem, MD, Professor of Neurology, Division Chief, UCSF Movement Disorder and Neuromodulation Center Weill Institute for Neurosciences, University of California San Francisco
Support for this program provided by Medtronic

Spotlight on Parkinson's Disease: Enhancing Communication About OFF
Speaker, Rebecca Gilbert, MD, PhD, and Vice President, Chief Scientific Officer, American Parkinson Disease Association
Support for this program provided by Acorda Therapeutics

Spotlight on Parkinson's Disease: Staying Healthy, Keeping Fit
Terry Ellis, PhD, PT, NCS, Assistant Professor, Department of Physical Therapy & Athletic Training, Director, Center for Neurorehabilitation, Boston University, College of Health & Rehabilitation Sciences: Sargent College, Boston, MA
Support for this program provided by Lundbeck, and Joan and Ross Collard

Spotlight on Parkinson's Disease: Understanding Dyskinesia
M. Maral Mouradian, MD, William Dow Lovett Professor of Neurology, Director, Center for Neurodegenerative and Neuroimmunologic Diseases, Rutgers Robert Wood Johnson Medical School, Piscataway, NJ
Support for this program provided by Adamas Pharmaceuticals, Inc.

Spotlight on Young Onset: Exploring Treatment and Management Options
Joel S. Perlmutter, MD, Elliot Stein Family Professor of Neurology, Section Chief of Movement Disorders, Professor of Radiology, Neuroscience, Physical Therapy, and Occupational Therapy, Washington University School of Medicine, St. Louis, MO
Support for this program provided by APDA

RESEARCH UPDATE

RESEARCH VIDEO LAUNCH

In October 2017, APDA launched our first-ever research video to showcase the impact and progress we have made in the research arena. The video highlights the urgent need to advance science that can help stop the disease's 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 PD. With both long (12 minute) and short (3 minute) versions of the video, we are better able to showcase this important aspect of our work.

APDA RESEARCH PROGRAM

APDA has been a funding partner in many major PD scientific breakthroughs, investing nearly $49 million in research since 1961. We are purposeful in our approach and want to make sure people understand the strategy behind our research funding, as well as the research and researchers we support.

As part of our 2018–2019 funding cycle, APDA awarded:

- More than $1.7 million to support cutting-edge PD research
- A prestigious George C. Cotzias Fellowship
- Two post-doctoral fellowships
- 11 research grants
- Funding for eight APDA Centers for Advanced Research

FELLOWSHIP

The George C. Cotzias Fellowship
This fellowship is awarded to a young physician-scientist with exceptional promise. The award spans three years and is designed to fund a long-range project focused on PD. This year's awardee is:

Aasef G. Shaikh, MD, PhD
Cleveland VA Medical Center and Case Western Reserve University, Cleveland, OH

He will investigate the influence of basal ganglia, thalamus and cerebellum network on discordant visual-input-induced gait disorder in PD. The project aims to understand how PD interferes in the brain pathways that maintain gait and balance.

(Learn more about Dr. Shaikh on page 20.)

> *"If we better understand the brain circuitry, we may be able to find the right place to stimulate with DBS to prevent falls, a major problem for many people with PD, which is not adequately addressed with current treatment strategies."*
>
> – Aasef G. Shaikh, MD, PhD

POST-DOCTORAL FELLOWSHIPS

These post-doctoral Fellowships are awarded to support post-doctoral scientists whose research holds promise to provide new insights into the pathophysiology, etiology and treatment of PD. This year's awardees are:

- **Daniel Joyce, PhD,** Stanford University, Stanford, CA
  He is studying pupil-based biomarkers of PD.

- **Giulietta Riboldi, MD,** The Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders (NYU Langone Health), New York, NY
  She is researching the role of GBA mutations in the pathogenesis of PD.

(Learn more about Dr. Riboldi on page 19.)

RESEARCH GRANTS

These research grants are awarded to investigators performing innovative PD research at major academic institutions across the United States. This year's awardees and their areas of study are as follows:

- **Tim Bartels, PhD**, Brigham and Women's Hospital, Boston, MA
  Alpha-synuclein related lipid pathology in PD
- **Christopher Bishop, PhD**, Binghamton University, Binghamton, NY
  Targeting the Pedunculopontine Tegmental Nucleus to optimize treatment of PD
- **Shu Chen, PhD**, Case Western Reserve University, Cleveland, OH
  Novel knockin models linking Rab phosphorylation to neurodegeneration in PD
- **Elizabeth Disbrow, PhD**, Louisiana State University Health Sciences Center, Shreveport, LA
  Diversity in biomarker discovery
- **Yuanfang Guan, PhD**, University of Michigan, Ann Arbor, MI
  Digital biomarkers for monitoring PD
- **Mallory Hacker, PhD**, Vanderbilt University Medical Center, Nashville, TN
  Investigating long-term clinical outcomes of Subthalamic Nucleus Deep Brain Stimulation in early-stage PD
- **Magdalena Ivanova, PhD**, University of Michigan, Ann Arbor, MI
  Biochemical and structural studies of alpha-synuclein fibrils derived from brain tissues with PD and dementia with Lewy bodies with Alzheimer's disease

- **Cameron Jeter, PhD**, The University of Texas Health Science Center, Houston, TX
  Protective role of the oral microbiome in PD
- **Eunsung Junn, PhD**, Rutgers, The State University of New Jersey, Piscataway, NJ
  In vivo identification of microRNAs associated with alpha-synuclein mRNA
- **Roberta Marongiu, PhD**, Weill Cornell Medical College, New York, NY
  Menopause as an important transition state in the susceptibility to PD
- **Talene Yacoubian, MD, PhD**, University of Alabama at Birmingham School of Medicine, Birmingham, AL
  Rab27b as a potential regulator of alpha-synuclein spread

APDA CENTERS FOR ADVANCED RESEARCH

APDA's Centers for Advanced Research support large PD research programs, which include research trainees, fellowship programs, early-stage discovery programs and later-stage clinical translation. These centers facilitate research that is at the forefront of investigation into the cause, treatment and, ultimately, cure for PD. This year, two new centers were chosen through a competitive application process: **Mayo Clinic, Jacksonville, FL and Brigham and Women's Hospital, Boston, MA**.

Boston University School of Medicine
– Boston, MA

Marie Hélène Saint-Hilaire, MD, FRCP (C)

Brigham and Women's Hospital
– Boston, MA

Clemens R. Scherzer, MD

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

David G. Standaert, MD, PhD

Mayo Clinic
– Jacksonville, FL

Dennis W. Dickson, MD

Emory University School of Medicine
– Atlanta, GA

Mahlon R. DeLong, MD

University of Pittsburgh Medical Center
– Pittsburgh, PA

J. Timothy Greenamyre, MD, PhD

Rutgers Robert Wood Johnson School of Medicine
– New Brunswick, NJ

Mary Maral Mouradian, MD

Washington University School of Medicine
– St. Louis, MO

Joel S. Perlmutter, MD

RESEARCHER STORIES

APDA is proud to support some of the most innovative scientists working in the field of PD research.

Giulietta Riboldi, MD
The Marlene and Paolo Fresco Institute
for Parkinson's and Movement Disorders,
NYU Langone Health, New York, New York

Dr. Riboldi is a post-doctoral fellow at the Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders at NYU Langone in New York City. She is the recipient of one of APDA's post-doctoral fellowships for the 2018–2019 academic year for her work studying how mutations in a protein called glucocerebrosidase (GBA) lead to the development of PD.

GBA is an enzyme that breaks down a large molecule in cells called glucocerebroside. When both copies of the GBA gene are mutated, glucocerebroside accumulates in cells, causing Gaucher's disease. Mutations in one or both copies of the GBA gene is also a genetic risk factor for the development of PD. However, only a small percentage of people with one GBA mutation develop the disease, and it is not yet clear why some people with the mutation develop PD while others do not. Dr. Riboldi's project investigates whether interactions with other genetic changes are responsible for why GBA mutations contribute to disease in only some people and not others.

> *“There are two main drivers of my work as a doctor and a research scientist. First is curiosity for understanding disease — why it develops, how it manifests, and what may be done to provide treatment and care. I know that there are answers out there that just need to be discovered.*
>
> *Second is the continuous support and encouragement that I receive from my patients. This reminds me why medical research is important and keeps me focused on doing my part in the care and potential cure of PD.”*
>
> – Giulietta Riboldi, MD

Aasef G. Shaikh, MD, PhD
Assistant Professor of Neurology, Case Western Reserve University, Cleveland, Ohio
Staff Neurologist, Cleveland VA Medical Center & University Hospitals

Dr. Shaikh is the recipient of APDA's prestigious three-year George C. Cotzias Fellowship for 2018-2021. His research focuses on the complex interactions of various neurologic systems, their effects on gait and balance in PD, and how they can be modified by Deep Brain Stimulation (DBS). The systems that Dr. Shaikh studies include: vision, eye movements, the inner ear/vestibular system and proprioception.

The overarching goal of his research program is to develop a DBS-based therapeutic approach to improve balance, gait and postural instability in PD. He feels that if we can better understand the brain circuitry, we may be able to find the right place to stimulate with DBS to prevent falls, a major problem for many people with PD, which is not adequately addressed with current DBS strategies.

Dr. Shaikh uses a unique motion delivery system that measures balance in PD patients. This type of system is normally used by NASA (or other space agencies) to train astronauts! In his lab they have modified this system to study postural control and balance function in PD, critical to preventing falls. They are the only group utilizing such a state-of-the-art system in combination with DBS to understand how DBS can be used to improve balance function in PD.

> *“Enthusiasm and the support of my patients drives my passion. Talking to patients and knowing their personal experiences about their disease and treatment is critical to finding novel ways to treat their problems. Such conversations fuel my passion for research.*
>
> *In addition, our research frequently leads us to new questions that we did not previously think to ask. Sometimes that question and its answer lead us in a completely new direction. The process continues, with one set of questions leading to the next, fueling the growth of our research program.”*
>
> – Aasef Shaikh, MD, PhD

AMERICAN PARKINSON DISEASE ASSOCIATION SCIENTIFIC ADVISORY BOARD

APDA Scientific Advisory Board: (Back row L-R) Joel S. Perlmutter, MD, Washington University School of Medicine; Dennis W. Dickson, MD, Mayo Clinic, Jacksonville; Un Jung Kang, MD, New York Langone Fresco Institute for Parkinson's and Movement Disorders; Richard Myers, PhD, Boston University School of Medicine; David G. Standaert, MD, PhD, Chairman of the APDA SAB, University of Alabama at Birmingham; Patrick McDermott, Chairman, APDA Board of Directors; Clemens R. Scherzer, MD, Harvard Medical School and Brigham & Women's Hospital; Vivek K. Unni, MD, PhD, Oregon Health & Science University. (Front row L-R); Mary Maral Mouradian, MD, Rutgers Robert Wood Johnson Medical School: Marie Hélène Saint-Hilaire, MD, FRCP (C), Boston University School of Medicine; Leslie A. Chambers, President & CEO, APDA; Rebecca Gilbert, MD, PhD, VP and Chief Scientific Officer, APDA; J. Timothy Greenamyre, MD, PhD, University of Pittsburgh Medical Center. (Not pictured); Mahlon R. DeLong, MD, Emory University School of Medicine; Laura Marsh, MD, Michael E. DeBakey VA Medical Center; Jill L. Ostrem, MD, University of California San Francisco; Evan Yale Snyder, MD, PhD, The Burnham Institute.

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

OUR GRASSROOTS NETWORK

Participants from the Midwest Chapter's walk in Chicago, Illinois.

APDA OPTIMISM WALK EVENT SERIES

It was another great year for the Optimism Walk — APDA's signature fundraising event series. From 2017 to 2018, the Walk program grew 29% in revenue. Highlights include:

- Northwest Chapter, whose Walk raised more than $128,000, a 44% increase, and saw a tremendous spike in participation with more than 600 participants
- Greater St. Louis Chapter, which saw a 36% growth in fundraising, bringing in more than $145,000 and more than 560 walkers
- Massachusetts Chapter raised more than $145,000, up 26% from last year, and had a great turnout of 450 walkers

Thank you to our 2018 Optimism Walk National Sponsors: AbbVie, Adamas Pharmaceuticals, Lundbeck and Sunovion Pharmaceuticals

CHAPTER MILESTONE!

The APDA Northwest Chapter's annual *Magic of Hope* Auction & Gala hit an exciting milestone. For the first time ever, it raised more than $500,000 in one evening! The event, held in Seattle, WA, was a magical evening with nearly 500 guests enjoying cocktails, dinner, a silent auction, fun games and raffles. The bidding war was fierce during the live auction, with items going for double and triple value! Guests came prepared to donate generously to the cause, and when the night was over, a record-breaking $505,000 was raised to help fight PD.

APDA President & CEO Leslie Chambers with Kirsten Richards, Jean Allenbach and Dwight Jones of the APDA Northwest Chapter at the Magic of Hope Auction & Gala.

JOINING FORCES

Guest enjoying a fun evening of dinner and dancing at the biennial APDA New England Regional Conference this past October.

Individually, our APDA chapters across the country do tremendous work every day and we're constantly impressed by and grateful for their tireless efforts to serve their local PD communities. Every two years, four of these chapters join forces and the result is something special. In October, the APDA Massachusetts, Connecticut, Rhode Island and Vermont Chapters once again banded together for the biennial APDA New England Regional Conference, where 800 attendees participated in a two-day program featuring educational PD information, 26 exhibitors and a fun evening of dinner and dancing.

A HOLE IN ONE FOR PARKINSON'S!

The APDA Greater St. Louis Chapter hosted their 20th Annual Golf Classic in Memory of Jack Buck in 2018. The sold-out tournament to support local Parkinson programming, service and research, raised more than $195,000 -- a new fundraising record for this event or any fundraiser hosted by the Greater St. Louis Chapter! The golfers enjoyed a wonderful day of great golf in spite of the heat and occasional drizzle. Other highlights included:

- A Q&A session with John Mozeliak, President of Baseball Operations for the St. Louis Cardinals, and Tom Ackerman, Sports Director at KMOX radio.
- Guest speaker Chris Burgess describing the challenges that PD presents for her husband, Ralph and the benefits of participating in local exercise classes offered at APDA.
- Dr. Joel Perlmutter sharing research progress and exciting studies taking place at the APDA Center for Advanced Research at Washington University School of Medicine.
- An exciting auction, raising $23,800, led by auctioneer Tom Ackerman.
- A successful Fund-a Need, with guests donating more than $36,000 to support the PD programs and services the Chapter provides.

The 2019 APDA Golf Classic takes place on May 20, 2019.

From left to right: Tom Ackerman, Debbie Guyer, Dr. Joel Perlmutter and John Mozeliak

MUSIC TRIVIA FOR A GREAT CAUSE

The 2018 Pennies for Pearls Music Trivia Champions.

The APDA Oklahoma Chapter held its 7th Annual Pennies for Pearls fundraiser in March 2018 at the Hard Rock Café in Tulsa. This fun event revolves around music trivia, where each table of attendees competes against each other to see who will go home the music trivia champion.

Shae Rozzi, Evening Anchor at Fox23 in Tulsa emceed the 2018 event with more than 400 people in attendance. They raised almost $80,000!

The 8th Annual Pennies for Pearls event will be held on April 6, 2019 at the Hard Rock Café in Tulsa.

13.1 MILES FOR PARKINSON'S

While the 7th Annual Parkinson's Half Marathon held on April 7, 2018 brought record cold temperatures, the frigid weather didn't stop more than 1,300 runners and walkers from turning out to run and raising more than $83,000 for the APDA Wisconsin Chapter. The warmth of friendship and dedication shared by volunteers, participants, and their supporters created atmosphere of celebration long after the last runner crossed the finish line.

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 unshakeable community. Since 2012, this dedicated group has organized the Parkinson's Half Marathon & 5k just outside of Madison and have collectively raised more than $325,000 for the APDA Wisconsin Chapter to support their programs and public education.

The 8th Annual Parkinson's Half Marathon takes place on April 6, 2019.

The Nasett Family

FIRST TIME'S A CHARM

Alice Lazzarini, PhD

APDA's Virginia-based Information & Referral Center and Chapters collaborated to host the first biennial APDA Virginia Parkinson's Education Day on October 7, 2017. More than 325 people with PD and their family members came together in Williamsburg for a full day of informative presentations and break-out sessions presented by knowledgeable and caring experts. A highlight of the day was a talk from Alice Lazzarini, PhD, author of *Both Sides Now: A Journey from Researcher to Patient.* Dr. Lazzarini shared her incredible journey as an internationally recognized researcher in neuro-genetic disorders and a member of the research team that discovered PARK1 and first associated the tau protein with Parkinson's, as well as her own diagnosis of Parkinson's.

The 2nd APDA Virginia Parkinson's Education Day will take place on September 28, 2019. For more information, contact the APDA Hampton Roads Chapter.

APDA LEADERSHIP (AS OF DECEMBER 31, 2018)

EXECUTIVE COMMITTEE

Chairman:
Patrick McDermott

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

Secretary:
Sally Ann Esposito Browne

Treasurer:
Elena Imperato

David J. Butler

Athol Cochrane

Mario J. Esposito, Jr.

DIRECTORS

Elizabeth Braun, RN

Lisa Esposito, DVM

Donna J.C. Fanelli

Michael Melnicke

Joel A. Miele Jr.

David G. Standaert, MD, PhD

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

Senior Vice President, National Programs and Partnerships
Robin Kornhaber, MSW

Senior Vice President of Development & Marketing:
Stephanie Paul

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

HONORARY PAST CHAIRMEN OF THE BOARD OF DIRECTORS

Fred Greene

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 outstanding stewards of donors' trust and ensure that administrative and fundraising costs are kept to a minimum.

Since 1961, APDA has invested more than $185 million to fund research, provide patient services and education, and elevate public awareness. The 2018 financial highlights follow. The entire audited financial statement and most recent IRS Form 990 are available at **www.apdaparkinson.org/about-apda/financial-reports/**.

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

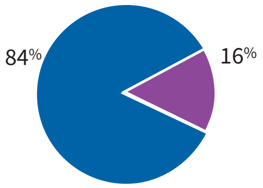
AMERICAN PARKINSON DISEASE ASSOCIATION, INC.
STATEMENTS OF FINANCIAL POSITION

	August 31, 2018	August 31, 2017
ASSETS		
Cash and equivalents	$ 6,727,039	$ 7,681,187
Bequests receivable, net	403,053	405,733
Contributions receivable	10,261	57,298
Investments	2,351,433	1,730,847
Investments held for charitable gift annuities	71,035	50,155
Prepaid expenses and other assets	373,549	359,156
Property and equipment, net	2,458,987	2,555,722
Total Assets	$ 12,395,357	$ 12,840,098
LIABILITIES AND NET ASSETS		
LIABILITIES:		
Accounts payable and accrued expenses	$ 556,422	$ 406,621
Deferred revenue	220,390	188,626
Grants payable, net	1,252,745	1,109,386
Charitable gift annuities payable	64,786	47,274
Total Liabilities	2,094,343	1,751,907
COMMITMENTS		
NET ASSETS:		
Unrestricted net assets	7,672,033	8,707,244
Temporarily restricted net assets	2,456,037	2,208,003
Permanently restricted net assets	172,944	172,944
Total Net Assets	10,301,014	11,088,191
Total Liabilities and Net Assets	$ 12,395,357	$ 12,840,098

STATEMENTS OF ACTIVITIES WITH COMPARATIVE TOTALS FOR 2017

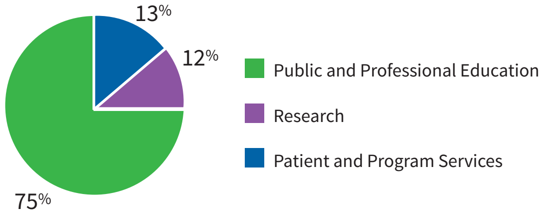
				August 31,	
				Total	
	Unrestricted	Temporarily Restricted	Permanently Restricted	2018	2017
SUPPORT AND REVENUES:					
Contributions	$ 5,542,938	$ 1,062,593	$ -	$ 6,605,531	$ 5,507,124
Legacies, bequests and estates	815,573	458,093	-	1,273,666	3,810,596
Special events	2,368,288	294,452	-	2,662,740	2,354,185
Investment return	317,276	-	-	317,276	316,836
Contributed services	9,366,367	-	-	9,366,367	10,653,917
Other revenue	27,548	-	-	27,548	47,292
	18,437,990	1,815,138	-	20,253,128	22,689,950
NET ASSETS RELEASED FROM RESTRICTIONS	1,567,104	(1,567,104)	-	-	-
Total support and revenues	20,005,094	248,034	-	20,253,128	22,689,950
EXPENSES:					
Program Services:					
Patient and program services	2,338,986	-	-	2,338,986	2,122,083
Research	2,126,228	-	-	2,126,228	1,974,304
Public and professional education	13,075,236	-	-	13,075,236	14,034,024
Total program services	17,540,450	-	-	17,540,450	18,130,411
Supporting Services:					
Management and general	936,470	-	-	936,470	789,046
Fundraising	2,563,385	-	-	2,563,385	2,182,543
Total supporting services	3,499,855	-	-	3,499,855	2,971,589
Total expenses	21,040,305	-	-	21,040,305	21,102,000
CHANGE IN NET ASSETS	(1,035,211)	248,034	-	(787,177)	1,587,950
NET ASSETS, BEGINNING OF YEAR	8,707,244	2,208,003	172,944	11,088,191	9,500,241
NET ASSETS, END OF YEAR	$ 7,672,033	$ 2,456,037	$ 172,944	$ 10,301,014	$ 11,088,191

Fiscal Year 2018 Expense Composition



While it varies slightly from year to year, Fiscal Year 2018 Audited Financial Statement shows 84% of expense went toward APDA's mission while 16% went to Fundraising and Administration.

Fiscal Year 2018 Program Expense Composition



THANK YOU!

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

Thank you for all you do!

AMERICAN
PARKINSON DISEASE
ASSOCIATION

Strength in optimism. 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