

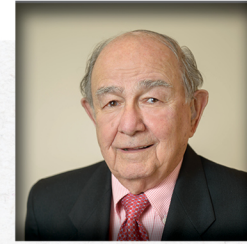
# OPTIMISM PROGRESS



2014 Annual Report



## *From the Chairman of the Board and President + CEO*



Dear Friends,

As we reflect on all of the milestones and accomplishments at the American Parkinson Disease Association (APDA) in 2014 we are struck by the diversity of this amazing organization. This was particularly evident as we worked together to create the 2015-2018 Strategic Plan. Our Strategic Planning Committee, chaired by Board Member, Patrick McDermott, worked throughout the year tapping into this diversity in every aspect of the planning process. The Committee was comprised of National and Field, Board Members and Staff representing a variety of important viewpoints throughout the organization. In addition, stakeholders including people with Parkinson's disease, care partners, scientists, clinicians, volunteers, and professional staff all participated in the formation of this plan.

We are extremely proud of the hard work throughout the organization in 2014 which advanced our dual purpose to *Ease the Burden — Find the Cure* for Parkinson's disease. In 2014, we enlarged our portfolio of funded research grants; we continued to support our outstanding group of eight Centers for Advanced Research; and connected with and supported people affected by Parkinson's throughout the entire country. This was accomplished by raising critical funds to support our mission programs and increasing our visibility in local

communities throughout the country. These accomplishments were only possible through the ongoing commitment of hundreds of volunteers, professional staff, and thousands of generous donors throughout the country.

As Chairman of the APDA Board of Directors and President & CEO, we are not only humbled and awed by the grassroots support and work of our national organization but also by the countless, steadfast donors who make our work possible. We wish to thank each and every one of you who have made a difference in the lives of families struggling with Parkinson's disease. We have accomplished great advances in the areas of support and research. Together, we are confident that we will continue to make great progress so that one day — hopefully soon — we can live in a world without Parkinson's disease.

Warm Regards,

A handwritten signature in dark ink, appearing to read "Fred Greene".

Fred Greene  
Chairman of the Board

A handwritten signature in dark ink, appearing to read "Leslie A. Chambers".

Leslie A. Chambers  
President & CEO



# 2015-2018 Strategic Plan

## Strategic Goals

**Vision:** *Ease the Burden – Find the Cure*

**Mission:** to provide information, education, and support to all impacted by Parkinson's disease and to fund scientific research into the causes, prevention, treatments and ultimately the cure.



1. **Deliver Innovative Programs and Services** – Provide innovative signature programs and services to all impacted by Parkinson's across the disease continuum and increase annual program participation.
2. **Support and Expand Parkinson's Disease Research** – Increase APDA research funding allocation by at least 25% by 2018 and advance research efforts in Parkinson's through continued advocacy, collaboration and funding of the most promising clinicians and scientists.
3. **Increase Public Awareness of Parkinson's Disease and APDA** – Increase the public's awareness of Parkinson's disease as a major health issue, and of APDA as a leader in the Parkinson's disease arena by broadening the reach of APDA messaging by at least 25% by 2018.
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.
5. **Enhance Organizational Capacity to Execute Mission and Revenue Goals** – Develop and sustain the infrastructure required to execute annual mission and revenue goals, and ensure consistent capability throughout the organization.





**APDA serves patients and family members through our nationwide network of Chapters and Information and Referral Centers.**

APDA's nationwide network provides information and referral, education and support programs, health and wellness activities, and events to facilitate a better quality of life for the Parkinson's community. It is this grassroots structure that distinguishes APDA from other organizations serving people with Parkinson's disease.

We are a local presence that can be counted on to extend a helping hand and to connect people to community resources for assistance.

### **Information and Referral Centers**

Seeing a physician who specializes in the care of Parkinson's patients (a neurologist and/or a neurologist who is a movement disorder specialist) has been shown to provide some of the best outcomes for a patient and an opportunity to learn about new treatments and clinical trials. APDA's Information and Referral Centers provide exemplary service and care to the Parkinson's community. Each center is staffed by a professional healthcare coordinator and overseen by a Parkinson's specialist who voluntarily provides medical direction for the Center.

APDA provides unique resources for specialized patient populations and maintains three nationally dedicated centers:

**The Young Onset Center** offers assistance to those who are diagnosed early in life and have unique concerns.

**The Resource Center for Rehabilitation** offers hope for a better quality of life through research-driven improvements in therapy.

**The Veterans Center** is dedicated to supporting and improving the lives of Veterans with Parkinson's disease.



## Education and Support Programs

- People with Parkinson's and Care Partner Support Groups
- Young Onset Support Groups
- Workshops
- Educational Literature



## Health and Wellness Programs

- Rowing • Boxing • Dancing • Singing
- Tai Chi • Yoga





“I will not let it defeat me.”



*“I will not let it defeat me.”* These are the determined words of ex-police officer **Allan Bleich** who was diagnosed with PD at age 45. As the President of the APDA New Jersey Chapter, Allan led a statewide effort to increase knowledge of the disease by pushing to pass the Parkinson’s Disease Public Awareness and Education Act A-2576 (S-1173). The bill requires the State Department of Health to reach out to the public through local boards of health, doctors and hospitals; provide educational programs to healthcare providers about research findings; and teach judicial staff, police officers, firefighters, and social services staff and EMS providers how to recognize PD symptoms and respond to the needs of people with the disease. The bill signed into law by NJ Governor Chris Christie in 2014 is the first state law in the country intended to raise public awareness and create educational programs about Parkinson’s disease.



**Every nine minutes** another person hears the words, “you have Parkinson’s disease.” This is a life-changing moment not only for a newly diagnosed individual, but also for his or her family, friends and community. APDA’s mission is to support each person’s journey so that the challenges of living with Parkinson’s can be addressed while life is lived to the fullest and with optimism.



**Carolyn** was a happy, healthy, fun-loving teenager when she first experienced a tremor in her right hand. She thought nothing of it. By the age of 19, she started dropping things, having persistent headaches, and experiencing bouts of losing consciousness. At the age of 22, Carolyn was diagnosed with Young Onset Parkinson’s disease. *“Devastation does not begin to express what I felt. I was young, vibrant and full of dreams for my future, and now that was all gone. My life was over, or so I thought,”* says Carolyn. She decided to reach out to others in the Parkinson’s community and found that APDA was hosting a conference a few hours from her home. *“After the conference I became very open and wasn’t ashamed to admit that my body isn’t well. I surrounded myself with people who saw me as a strong, beautiful, capable woman, not a weak, sick, shaky girl,”* she says. *“Get involved, reach out to people who have been there (there’s no reason to feel alone, someone somewhere is feeling what you have felt) learn as much as you can, and allow yourself to feel. I have a rule that I am allowed to feel sad or even bad for myself but never for two days in a row. Always find the positive to come back to.”*



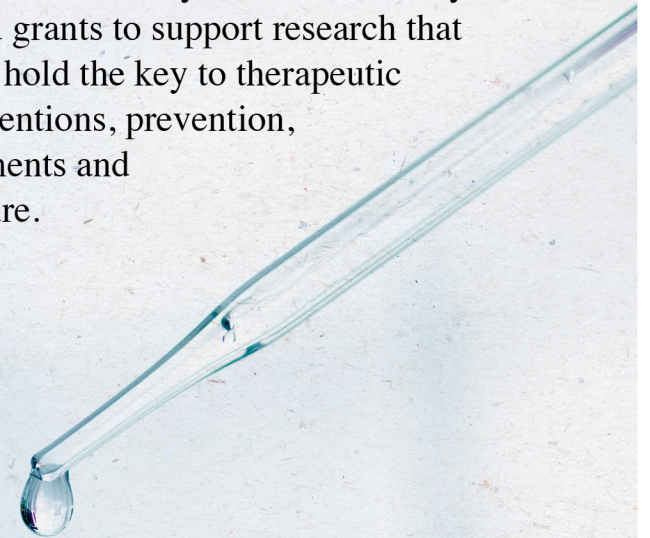
**APDA has contributed more than \$42 million to scientific research and has been a funding partner in most major Parkinson's disease scientific breakthroughs in the last fifty years.**

In the 2013-2014 academic year, APDA invested more than \$1.1 million to fund:

- Four Post-Doctoral Fellowships to support post-doctoral scientists whose research training holds promise into new insights of geriatric psychology, pathophysiology, etiology and treatment of Parkinson's disease
- Seven Research Grants to junior investigators pursuing research in Parkinson's disease
- Eight Centers of Advanced Research located in major academic and medical centers across the country intended to strengthen and help to integrate already existing investigative teams

### **Scientific Advisory Board**

APDA's Scientific Advisory Board is comprised of scientists with recognized expertise relevant to Parkinson's disease and leading edge research areas. The APDA Board of Directors reviews and votes on the recommendations provided by the Scientific Advisory Board. Then they award grants to support research that could hold the key to therapeutic interventions, prevention, treatments and the cure.





*“Without this support I would not be where I am today.”*

**Clemens R. Scherzer, M.D.**, Associate Professor of Neurology, Harvard Medical School and Brigham &

**Women’s Hospital:** *“It is a tremendous*

*honor for me to join the APDA Scientific*

*Advisory Board (SAB). As a recipient of the distinguished*

*APDA Cotzias award in 2004, I recognize how important*

*it is to encourage young neurologists to follow in*

*Dr. Cotzias’ footsteps in translating discoveries into*

*advances for treating movement disorders. Without*

*this support I would not be where I am today. It’s a*

*great privilege to have the opportunity to contribute*

*to the continued success of this*

*mission as a member of*

*the SAB.”*



*“We could stop Parkinson’s in its tracks.”*

**Talene Yacoubian, M.D., Ph.D.**

Assistant Professor, Department

of Neurology, University of

**Alabama at Birmingham:** *“As a researcher — and as*

*a physician treating Parkinson’s disease patients — the*

*experience of my own lab shows why APDA matters*

*so much. I had been thinking about the way certain*

*proteins fold the wrong way, spreading from one cell to*

*the next in the brains of people with Parkinson’s. Then*

*I had an idea that if only we could block the spreading*

*with another type of protein, we could stop Parkinson’s*

*in its tracks. I began to research this idea, but I didn’t*

*have the resources or the funding to get very far on my*

*own until APDA stepped in with the critical funding to*

*take my research to the next level. Thanks to APDA, my*

*lab is in its second year of research*

*on stopping the spread of*

*misfolding proteins.”*





## Scientific Advisory Board (as of December 2014)

### Chairman

David G. Standaert, M.D., Ph.D.  
John N. Whitaker Professor and  
Chair of Neurology  
University of Alabama at Birmingham,  
School of Medicine



### Members

James P. Bennett, Jr., M.D., Ph.D.  
Bemiss Professor of Neurology and Chair  
Virginia Commonwealth University

Marie-Francoise Chesselet, M.D., Ph.D.  
Charles H. Markham Professor  
UCLA David Geffen School of Medicine

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

Dennis Dickson, M.D.  
Professor of Laboratory Medicine  
& Pathology  
Mayo Clinic, Jacksonville, Florida

Un Jung Kang, M.D.  
H. Houston Merritt Professor of Neurology  
Columbia University College of Physicians  
and Surgeons

Laura Marsh, M.D.  
Professor of Psychiatry  
Michale E. DeBaakey VA Medical Center

Mary Maral Mouradian, M.D.  
William Dow Lovett Professor of Neurology  
Rutgers-Robert Wood Johnson Medical  
School

Richard Myers, Ph.D.  
Professor, Department Of Neurology  
Boston University School of Medicine

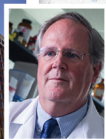
Joel S. Perlmutter, M.D.  
Elliot Stein Family Professor of Neurology  
Professor of Radiology, Neurobiology,  
Physical Therapy & Occupational Therapy  
Washington University School of Medicine

Marie H       Saint-Hilaire, M.D., FRCP (C)  
Associate Professor of Neurology  
Boston University School of Medicine

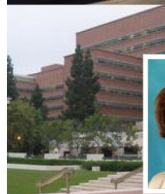
Evan Yale Snyder, M.D., Ph.D.  
Director, Stem Cell & Regeneration Program  
The Burnham Institute



# APDA Centers for Advanced Research received nearly \$700,000 in funding in 2014.



**David G. Standaert, M.D., Ph.D.**  
University of Alabama at Birmingham,  
School of Medicine



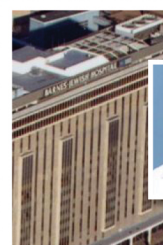
**Marie-Francoise Chesselet, M.D., Ph.D.**  
UCLA David Geffen  
School of Medicine



**Mahlon R. DeLong, M.D.**  
Emory University  
School of Medicine



**Marie Hélène Saint-Hilaire, M.D., FRCP (C)**  
Boston University  
School of Medicine



**Joel S. Perlmutter, M.D.**  
Washington University  
School of Medicine



**Lawrence I. Golbe, M.D.**  
Rutgers-Robert Wood Johnson  
Medical School



**J. Timothy Greenamyre, M.D., Ph.D.**  
University of Pittsburgh  
Medical Center



**Madaline B. Harrison, M.D.**  
University of Virginia  
Health System



# Fundraising Campaigns

## Funding Our Programs



Photo: Garet Munger

## Optimism Walk

Each year, thousands of people participate in Optimism Walk events to raise awareness and funds to *Ease the Burden — Find the Cure* for Parkinson's disease. Funds raised through the Optimism Walk Campaign support scientific research and APDA's Information and Referral network. In 2014, Optimism Walks were held in more than 25 U.S. cities and raised nearly \$700,000.

The Washington Chapter hosted their Inaugural Optimism Walk in Seattle with more than 300 walkers and 23 teams who braved gusting winds and heavy rain. It was a day full of optimism, hope, community and strength. Despite Mother Nature's obstacles, the Chapter raised more than \$45,000 far exceeding their goal of \$25,000.

The Massachusetts Chapter hosted its 28th Annual Optimism Walk at the Reebok International Headquarters in Canton, MA. Over 1000 walkers gathered raising more than \$150,000 to support a variety of activities including physical therapy, arts and movement, educational, and care partner programs.





## \$1 Million for 1 Million Campaign

- **Every 9 minutes** there is a new diagnosis.
- There are **60,000 diagnoses** of PD every year.
- Parkinson's disease is the **14th leading cause** of death in the U.S. and is estimated to cost our country at least \$14.4 billion annually.
- **1.6% of people** over the age of 65 are living with Parkinson's disease.

APDA launched **\$1 Million for 1 Million**, a **transformative two-year fundraising initiative** that will enable us to expand our dual purpose to *Ease the Burden — Find the Cure*. Our goal is to raise \$1 million dollars for one million people with Parkinson's disease. This critical support will help expand our current efforts and provide more service to those touched by Parkinson's disease. Programs that will be supported include:

- Health and Wellness initiatives that will support the delivery of signature exercise programs to be delivered throughout the APDA network.

- Education and support programs to broadly serve the Parkinson's community and offer the level of support needed for a disease that becomes the main event in day-to-day functioning and quality of life.
- Expediting the pace of research funding to support the most promising new clinical approaches in search of a cure.
- Playing a leading role in launching the careers of young physicians and scientists dedicated to working on Parkinson's disease as well as helping to bring promising new investigators into the field — many of whom are in the postdoctoral stages of their careers, and keep them there for the long term.

For more information, visit [apdaoptimism.org](http://apdaoptimism.org).





## Live With Optimism PSA

In 2014, APDA launched a new Public Service Announcement Awareness Campaign, “Live With Optimism.” The 60, 30 and 15 second TV and Radio spots are airing across the country to raise awareness and funding to continue our efforts to *Ease the Burden — Find the Cure*.

Visit [www.apdaoptimism.org](http://www.apdaoptimism.org)





# APPA Leadership (as of December 2014)

## Executive Committee

### *Chairman:*

Fred Greene

### *1st Vice Chair:*

Patrick McDermott

### *2nd Vice Chair:*

John Z. Marangos, Esq.

### *3rd Vice Chair:*

Elliot J. Shapiro, PE

### *Secretary:*

Jerry Wells, Esq.

### *Treasurer:*

Elena Imperato

Joseph G. Conte  
Nicholas Corrado  
Sally Ann Esposito Browne  
Vincent N. Gattullo  
Thomas K. Penett, Esq.  
William Powers

## Directors

Elizabeth Braun, RN  
Gary W. Chu  
Athol Cochrane  
Maxine Dust  
George A. Esposito Jr., Esq.  
Lisa Esposito, DVM  
Mario J. Esposito, Jr.  
Michael Esposito  
Donna J.C. Fanelli  
Marvin Henick  
John Lagana Jr.  
Michael Melnicke  
Joel A. Miele Jr., PE  
Michael Pietrangelo, Esq.  
David G. Standaert, M.D., Ph.D.  
Daniel Wheeler

## Emeritus Members

Donna Marie Foti  
The Hon. John Fusco  
Paul Gazzara, M.D.  
Michael Halkias  
Frank Petruzzi  
Robert Pierrello  
Dorothy Reimers  
Scott Scheffrin  
Jay A. Springer, Esq.  
Martin Tuchman

## Senior Staff and Specialized Center Directors

### *President & CEO:*

Leslie A. Chambers

### *Vice President of Chapter Development & Field Operations:*

Michelle Harman McDonald, MSW, LSW

### *Vice President Development and Marketing:*

Stephanie Paul

### *Controller:*

Cheryl Weiner

### *National Resource Center for Rehabilitation:*

Terry Ellis, PT, Ph.D., NCS

### *National Veterans Center:*

Susan Gulas, RN, MSN

### *National Young Onset Center:*

Julie Sacks, MSW, LCSW



# Financials

APDA is keenly aware of the many choices donors have in how charitable giving is directed. Since 1961, APDA has invested more than \$86 million to fund research, patient services and education, and elevate public awareness.

At the core of APDA's fiduciary responsibility is our ability to identify new ways to provide increased funding to maximize the support of our mission, while ensuring that our administrative and fundraising costs are kept to a minimum.

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

*The 2014 financial highlights follow. Full audited financials and our most recent IRS Form 990 is available at [www.apdaparkinson.org](http://www.apdaparkinson.org).*

## CONSOLIDATED STATEMENT OF FINANCIAL POSITION

### ASSETS

|                                       | 2014                 | 2013                |
|---------------------------------------|----------------------|---------------------|
| Cash                                  | \$ 5,520,805         | \$ 4,622,796        |
| Contributions and bequests receivable | 800,366              | 815,795             |
| Investments                           | 1,536,631            | 1,345,010           |
| Prepaid expenses and other assets     | 266,191              | 114,934             |
| Property and equipment - net          | 2,741,428            | 2,850,986           |
| <b>TOTAL ASSETS</b>                   | <b>\$ 10,865,421</b> | <b>\$ 9,749,521</b> |

### LIABILITIES AND NET ASSETS

|   |                      |                     |
|---|----------------------|---------------------|
| <b>LIABILITIES:</b>                     |                      |                     |
| Accounts payable and accrued expenses   | \$ 414,076           | \$ 558,253          |
| Grants payable                          | 2,402,273            | 2,354,810           |
| Annuities payable                       | 66,406               | 84,249              |
| <b>Total liabilities</b>                | <b>2,882,755</b>     | <b>2,997,312</b>    |
| <b>NET ASSETS:</b>                      |                      |                     |
| Unrestricted                            | 4,840,693            | 2,183,537           |
| Temporarily restricted                  | 2,969,029            | 4,395,742           |
| Permanently restricted                  | 172,944              | 172,930             |
| <b>Total net assets</b>                 | <b>7,982,666</b>     | <b>6,752,209</b>    |
| <b>TOTAL LIABILITIES AND NET ASSETS</b> | <b>\$ 10,865,421</b> | <b>\$ 9,749,521</b> |



## CONSOLIDATED STATEMENT OF ACTIVITIES

|  | Unrestricted      | Temporarily<br>Restricted | Permanently<br>Restricted | Total             |                  |
|--|-------------------|---------------------------|---------------------------|-------------------|------------------|
|  |                   |                           |                           | 2014              | 2013             |
| <b>REVENUE:</b>                          |                   |                           |                           |                   |                  |
| Contributions                            | \$ 3,747,528      | \$ 752,562                |                           | \$ 4,500,090      | \$ 4,233,893     |
| Legacies, bequests and estates           | 2,404,418         | 628,196                   | \$ -                      | 3,032,614         | 2,413,637        |
| Special events                           | 1,023,731         | 1,059,327                 | -                         | 2,083,058         | 1,998,666        |
| Investment income                        | 263,895           | 118                       | 14                        | 264,027           | 167,716          |
| Other revenue                            | 173,948           | -                         | -                         | 173,948           | 57,427           |
| Net assets released from restrictions    | 3,866,916         | (3,866,916)               |                           | -                 | -                |
| <b>Total revenue</b>                     | <b>11,480,436</b> | <b>(1,426,713)</b>        | <b>14</b>                 | <b>10,053,737</b> | <b>8,871,339</b> |
| <b>EXPENSES:</b>                         |                   |                           |                           |                   |                  |
| Program:                                 |                   |                           |                           |                   |                  |
| Information and referral centers         | 1,742,304         | -                         | -                         | 1,742,304         | 2,454,438        |
| Research                                 | 1,665,906         | -                         | -                         | 1,665,906         | 1,599,057        |
| Public and professional education        | 2,575,697         | -                         | -                         | 2,575,697         | 2,312,059        |
| <b>Total program services</b>            | <b>5,983,907</b>  | <b>-</b>                  | <b>-</b>                  | <b>5,983,907</b>  | <b>6,365,554</b> |
| Supporting Services:                     |                   |                           |                           |                   |                  |
| Administration                           | 692,427           | -                         | -                         | 692,427           | 864,546          |
| Fundraising                              | 2,146,946         | -                         | -                         | 2,146,946         | 1,839,160        |
| <b>Total supporting services</b>         | <b>2,839,373</b>  | <b>-</b>                  | <b>-</b>                  | <b>2,839,373</b>  | <b>2,703,706</b> |
| <b>Total expenses</b>                    | <b>8,823,280</b>  | <b>-</b>                  | <b>-</b>                  | <b>8,823,280</b>  | <b>9,069,260</b> |
| <b>(Decrease) Increase in net assets</b> | <b>2,657,156</b>  | <b>(1,426,713)</b>        | <b>14</b>                 | <b>1,230,457</b>  | <b>(197,921)</b> |
| Net assets, beginning of year            | 2,183,537         | 4,395,742                 | 172,930                   | 6,752,209         | 6,950,130        |
| Net assets, end of year                  | \$ 4,840,693      | \$ 2,969,029              | \$ 172,944                | \$ 7,982,666      | \$ 6,752,209     |



Our work is only made possible with  
friends and supporters like you.

Thank you for all you do!



**American Parkinson Disease Association**

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(800) 223-2732 • [www.apdaparkinson.org](http://www.apdaparkinson.org) • E-mail: [apda@apdaparkinson.org](mailto:apda@apdaparkinson.org)