

APDA Commemorates April Parkinson Awareness Month



Rachael Monaco, a teacher at Susan Wagner High School in Staten Island and her students representing Team Monaco at the Unity Walk.

APDA chapters across the nation came together as one during April to mark Parkinson's Disease Awareness Month. The activities chapters hosted for their communities and the outpouring of support they received, served as a testament to the energy, dedication, and unwavering commitment shared by so many people to fight this disease. Every nine minutes another person is diagnosed with Parkinson's, therefore there is always a new face, a new name in the Parkinson's disease family. That means there is another person and his or her network of caregivers – medical professionals, family, and friends – to support and to hopefully inspire to join the ranks and respond to the call to action to *Ease the Burden - Find the Cure*.

Chapters celebrated Parkinson's Disease Awareness Month in a variety of ways. In Arizona, the APDA Green Valley Branch hosted

Continued on page 2

SPRING 2014

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Fred Greene

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Advisory Board**
David G. Standaert, MD, PhD

President & CEO
Leslie A. Chambers

OUR MISSION

As the country's largest grassroots Parkinson's disease organization, the American Parkinson Disease Association (APDA) improves the lives people with Parkinson's disease and their families from coast to coast with patient/caregiver support; education and positive lifestyle programs; awareness, social and fundraising events; and scientific research funding at all levels. Through a national network of Chapters, Information & Referral Centers, support groups, and Centers for Advanced Research, APDA delivers help for today and hope for tomorrow.

APDA Scientific Advisory Board Meets to Recommend Awards

The American Parkinson Disease Association's Scientific Advisory Board (SAB) met in May to review more than 55 submissions all vying for a combined \$500,000 in funding that will be awarded to experienced and young scientists in the Parkinson's field. APDA's SAB is a prominent panel of the country's most outstanding neurologists and scientists who rigorously review the research applications and recommend funding of the most promising studies.

SAB members spent the day contemplating and debating the merits of each grant proposal while keeping in mind APDA's critical role in driving forward progress and supporting the researchers of the future. "What sets APDA apart is its track record of launching the careers of the best and brightest scientists working on Parkinson's disease, and enabling exploration of new ideas for finding the cure," commented Dr. David G. Standaert, Chairman of the SAB.

Sheng-Han Kuo, MD, PhD an APDA-funded junior researcher investigating the relationship of the most common of genetic mutations of PD, causes of cellular



APDA Scientific Advisory Board - Front row L-R: Mary Maral Mouradian, MD; Marie Saint Hillaire, MD; David Standaert, MD, PhD (SAB Chairman); Leslie A. Chambers, APDA President & CEO; Evan Yale Snyder, MD, PhD Back row L-R: Joel S. Perlmutter, MD; Mahlon R. DeLong, MD; Dennis Dickson, MD; Marie-Francoise Chesselet, MD, PhD; Richard Myers, PhD; James P. Bennett, Jr., MD, PhD.

Continued on page 2

APDA Commemorates April Parkinson Awareness Month *Continued from page 1*

an “Activity Day” with this year’s event attracting increased sponsorship from previous years, resulting in more than \$20K raised to support education and research. In San Antonio, Texas, the APDA chapter held its 18th annual Optimism Walk, “Shake, Rattle & Stroll,” and the St. Louis Chapter dedicated its resources during April to a series of courses to train caregivers, as well participated in the Go! St. Louis Marathon & Family Fitness Weekend. This was the chapter’s inaugural year and it was the top fundraising charity out of 30 selected to participate raising approximately \$60,000. The Georgia Chapter hosted its first Liberty Mutual Invitational Golf Event, and the Massachusetts Chapter ended the month with its 28th Annual-Optimism Walk. This walk continues to be among the top fundraising events drawing more than 1,500 people and raising approximately \$150,000. Other chapters held educational events, bowling events, and even pancake breakfasts to bring people together to raise funds and awareness.

The 20th Annual Unity Walk held in Central Park, New York was attended by the most walkers in its 20 year history and to date this year has raised more than \$1.5 million, which will be used for research funded by all the Parkinson’s disease organizations including APDA.

April not only brings with it the signs and sounds of spring, it brings with it hope. It is the hope that through the collective efforts of the country’s largest grassroots organization serving more than 1 million Americans with Parkinson’s disease and their families, we will continue doing what we did in April, making our communities aware of the people living amongst us with Parkinson’s. Doing this will bring us closer to finding the answers and finding the cure.



1. Team Rocking & Rolling gather at the APDA San Antonio Optimism Walk/Run in Texas.
2. Participants for the APDA Team participate in the Go! St. Louis Marathon & Family Fitness Weekend event.
3. Two thousand people participated in the 28th Annual Optimism Walk sponsored by the APDA Massachusetts Chapter at Reebok International Headquarters.

APDA Scientific Advisory Board Meets to Recommend Awards *Continued from page 1*

dysfunction and PD pathology at Columbia University said, “I can’t emphasize enough that as a junior investigator how important APDA funding is for high risk, high reward studies. This support has allowed me to start my own lab and gather the data needed to leverage additional funding from the National Institutes of Health and Columbia University.”

APDA is focused on advancing scientific research that will support its mission to *Find a Cure* for Parkinson’s disease. APDA has been a funding partner in most of the PD scientific discoveries in the last 50 years including the work of Dr. George C. Cotzias, which led to establishing the effectiveness of high oral doses of Levodopa in treating PD; the work of Dr. Roger Duvoisin and his team that led to identifying the role of heredity and environment in PD; the research of Dr. Menek Goldstein establishing the role of dopamine agonists in PD treatment; and the research at Robert Wood Johnson Medical Center, which led to the discovery of a mutation in the protein alpha-Synuclein, named PARK1.

2014 Grant funding will be announced in August.



ADPA Funded Researchers present progress reports to SAB (L-R) Talene Yacoubian, MD, PhD (University of Alabama at Birmingham); Theresa Ellis PhD (Boston University); David G. Standaert, MD, PhD, (SAB Chairman); Mian Cao, PhD (Yale University); Leslie A. Chambers, APDA President & CEO; Sheng-Han Kuo, MD, PhD (Columbia University); Laura Volpicelli-Daley, PhD (University of Alabama at Birmingham)

ASK THE DOCTOR *By Joseph H. Friedman, MD*



Joseph H. Friedman, MD

Q. I am a 54-year-old male who was diagnosed with Parkinson's two years ago. Although no link in my case has been established, I have worked as a pesticide applicator for more than fifteen years. Besides a reduced sense of smell, my symptoms include impaired, cramped writing and tremors

that began two or more years ago in my right thumb and advance to my right hand and wrist area last summer. My main question is, if pesticide exposure is a factor, will continuing to work in this field accelerate my Parkinson's or has the damage already been done? Also, is there any way to determine if pesticides are involved in my condition?

A. There have been many studies looking for associations between environmental agents, usually toxins, and PD. The most robust association is a negative one. People with PD are less likely to have smoked cigarettes. There have been associations, generally very small, between pesticide exposure, well water use and the development of PD. The Veterans Administration considers vets who spent any time on the ground in Viet Nam during the war as having a "service-connected" disability if they have PD. However, this does not mean that any of these exposures were causal. After all, James Parkinson described PD long before pesticides were in use. The short answer to your question is: we don't know if your exposure is connected to your PD. If it is, and there is no way to prove it is, then further exposure would seem like a bad idea. Since we don't know that further exposure is safe, it would seem prudent to stop the exposure, if at all possible.

Q. My father has Parkinson's disease and is now in a nursing home. He has developed "persecution" delusions, hallucinations and Capgras syndrome in the last three months. I know that without his full history, there is little you can help me with, so I just

want to know if there is any hope of getting him at least to a level where he can feel some contentment, rather than suffer every day. His doctors have tried this various medications and nothing seems to be helping.

A. Delusions and hallucinations are, unfortunately, fairly common in PD patients. For those who don't know Capgras' syndrome, it is a peculiar delusion (false and illogical belief) that someone or something has been replaced by its exact duplicate. A patient with Capgras' syndrome may report having a real wife and a duplicate wife who looks and sounds just like the real one. However they may also think their home is not their real home and that it just looks like the real home.

The first thing to do is check that all his medications are needed, especially if there are meds for the bladder, sleep, anxiety, etc. Then check to see if the PD meds can be reduced. Once the medications are at the lowest tolerable level one can treat following either of two schools of thought. American neurologists, like me, would recommend a trail of quetiapine, given at low doses at night. If a suitable trial of this drug was not helpful, I'd switch to clozapine, again using very low doses, given at night. These usually work within a few days, but not always, and may produce excess sedation. [These drugs are antipsychotic drugs, and have "black box" warnings, meaning that they increase the risk of death compared to not using them. I strongly suggest ignoring these warnings as the risks are extremely minute, and compared to the benefit your father might see, are infinitesimal]. The alternative approach, advocated by British geriatric psychiatrists, would be to use one of the Alzheimer dementia drugs. The problem with this choice is that they take a much longer time to produce a benefit. It is not clear to me that they are as effective as the anti-psychotic drugs. They've never been tested against each other so there is no data.

Joseph H. Friedman, MD, Chief of Movement Disorders Program at Butler Hospital in Providence, Rhode Island.

Materials concerning Parkinson's disease research and answers to readers' questions are solely for information and should not be used for treatment purposes, but for discussion with the patient's health care provider.

Medicare Expands Entitlement for PD Patients

An all too quiet change has happened that benefits people with Parkinson's disease (PD) and has been in effect since January 2014. Medicare officials updated the agency's policy manual to now state that not seeing improvement in a patient is not a reason to decline coverage for physical therapy, nursing care and other services. This is crucial to sustain independence and enhance quality of life for people with PD as physical therapy is a vital component of health and wellness.



As Terry Ellis PhD, a physical therapist and director of the APDA National Rehabilitation Resource Center noted, "physical therapy has been shown to improve walking ability, physical function, balance, strength and PD symptoms leading to reduced disability and greater independence in persons living with PD."

Dr. Ellis went on to say that "in order to optimize the benefit of physical therapy, exercise programs must be adapted and progressed to meet the changing needs of each individual with PD over time. This means that people with PD require access to physical therapy services to help them reach their potential."

The Medicare manual revisions were required as part of the settlement of a class-action lawsuit (*Jimmo v. Sebelius*) filed in 2011 by the Center for Medicare Advocacy and Vermont Legal Aid on behalf of four Medicare patients and five national organizations, including the National Multiple Sclerosis Society, Parkinson's Action Network and the Alzheimer's Association.

The settlement affects care from skilled professionals for physical, occupational or speech therapy, and home health and nursing home care, for patients in both traditional Medicare and private Medicare Advantage plans. Those seeking coverage should refer to: http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/SNFPPS/Downloads/jimmo_fact_sheet2_022014_final.pdf.

With this important change people with PD may be able to get the care they need to continue to maintain as much mobility as possible.

The settlement also establishes a special "re-review" procedure for claims that were denied in the past three years solely because patients were not improving or because their care was intended to maintain their condition.

The following link offers a form beneficiaries can use to request reimbursement if they paid for care for themselves: https://www.q2a.com/Portals/0/JIMMO_REREVIEWFORM-508.pdf.

The form must be submitted by July 23, 2014 for claims with a final denial dating from Jan. 18, 2011, through Jan. 24, 2013. Requests for review of denials received Jan. 25, 2013, through Jan. 23, 2014, are due Jan. 23, 2015.



Dr. Terry Ellis, a physical therapist and Director of the APDA National Rehabilitation Resource Center, has PT consultation with an individual at the Unity Walk.

APDA Launches National Public Service Announcement Campaign

“I have Parkinson, but Parkinson’s does not have me, “ said Elke.

“Life is meant to be lived and enjoyed, not to be spent dwelling on a “little thing” like PD,” said Helen.

These comments so eloquently reflect the purpose and goal of the Public Service Announcement campaign (PSA) – *Live with Optimism* – being launched by the American Parkinson Disease Association in September.

The individuals who made those comments are the “heart and soul” of the 60 second TV, radio PSA and print ads that will be distributed nationwide with the goal of instilling the idea that despite a PD diagnosis people can still live with dignity and Optimism. The PSA encourages everyone to join the call to action to help *Ease the Burden – Find the Cure* for Parkinson’s disease.

The PSA was the brainchild of veteran actor Larry Strauss, who has PD, and film producer/director Autumn McAlpin who contacted APDA in January with the idea. “We jumped on this opportunity” says Leslie Chambers, APDA President & CEO, “because there is a tremendous need to educate the general public about Parkinson’s, who it affects and to call attention to the urgency to end this disease especially as our population ages and more and more people are diagnosed.”

Funded in part by a generous grant from the Missouri Fraternal Order of Eagles, the PSA was filmed and produced on the West Coast in the Laguna Woods community of Orange County, California. The 15, 30 and 60-second spots show actual people with PD living their lives despite their disease. These stories serve as a way to illustrate the Optimism they live with and aims to inspire others to share in this Optimism.

This PSA campaign is just one example of how APDA continues to look for avenues to remind people that together we can put an end to this disease and help the more than 1 million people in the United States who live each day with Parkinson’s.

Be on the lookout for the PSAs to appear on TV, radio and in print in your community starting in September. APDA will also be launching a dedicated microsite to allow everyone to read these stories of Optimism, share their own stories, learn how APDA provides local support to those coping with Parkinson’s and finally, to help raise critical funds for Information & Referral services, education and wellness programs throughout the country.



Director Autumn McAlpin checks a shot while makeup artist April Bautista prepares Larry Strauss and Elke Ballweg as they prepare for a scene in the PSA.



Larry Strauss, PD patient and producer of PSA poses with Stephanie Paul, APDA VP of Development & Marketing.

Annual Report - Reflections on 2013

Dear APDA Supporter,

Nearly 200 years since Dr. James Parkinson published his paper “Shaking Palsy” in 1817, there are still 164 people who are diagnosed every day in the United States with Parkinson’s disease. With an economic impact of \$14.4 billion annually and a future in which more and more of our aging population will be diagnosed with this neurodegenerative disease that has no cure, the time is now to change the landscape of PD.



Mr. Greene



Ms. Chambers

The American Parkinson Disease Association is tremendously proud of its 50+ year history, having distinguished itself as the country’s largest grassroots organization serving more than 1 million Americans with the disease. We have contributed more than \$80 million to patient/caregiver support, education and research. Through this investment we have been a funding partner in most of the major scientific breakthroughs in Parkinson’s disease research. But it is simply not enough.

2013 served as an important year of transition for APDA laying the groundwork for our future. Research funding was a critical accomplishment as we awarded more than \$1.1 million in seven research grants, four post-graduate fellowships, and funding for centers for advanced research at eight major academic and medical centers across the country.

More than \$4.7 million in funding was allocated to support education, local Information and Referral centers, chapters and Support Groups. These programs provide education and support on a local level through symposiums and lectures, distribution of literature, newsletters, maintaining websites, and providing support for patients, care partners, and healthcare professionals throughout the country.

In June 2013, more than 100 people attended the APDA Leadership Conference in Nashville. This professional education program was attended by chapter and I&R leadership with conference objectives to inform those who serve people with PD of the latest scientific research, therapies, and available resources; to empower PD patients and their caregivers to be informed partners in their treatment and to provide the newest tools for high quality of life to PD patients.

Looking ahead, under the direction of the APDA National Board of Directors and national staff in collaboration with our network volunteers and local staff we have embarked on an ambitious plan to build a strategic plan that will set the stage for the next decade of our work and take us through 2015-2018. Our goal is to strengthen our impact in local communities through the delivery of high quality patient services, a well-trained, competent workforce of staff and volunteers, and a robust portfolio of cutting edge science designed to further our work into finding the cure for Parkinson’s. The strategic plan will focus on mission advancement, innovation in fundraising, expanding leadership capacity and building an organizational structure to support these ambitious goals.

We are forever grateful for the ongoing support of our chapters, I&R centers, support groups, donors and researchers and look to a year filled with Optimism and renewed strength in fighting the battle against Parkinson’s disease.

A handwritten signature in black ink that reads "Fred Greene".

Fred Greene
Chairman, National Board of Directors

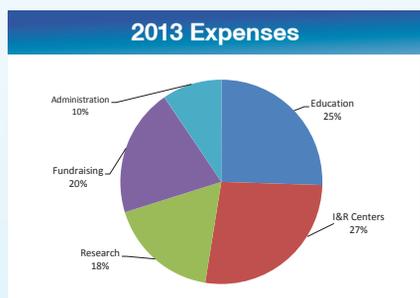
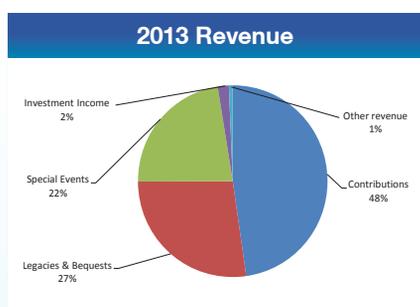
A handwritten signature in black ink that reads "Leslie A. Chambers".

Leslie A. Chambers
President & CEO

STATEMENTS OF ACTIVITIES FOR THE YEAR ENDED AUGUST 31, 2013

| | Unrestricted | Temporarily Restricted | Permanently Restricted | TOTAL | |
|---------------------------------------|------------------|------------------------|------------------------|------------------|------------------|
| | | | | 2013 | 2012 |
| REVENUE: | | | | | |
| Contributions | \$3,028,334 | \$1,205,559 | | \$4,233,893 | \$4,338,571 |
| Legacies, bequests and estates | 1,696,421 | 707,696 | \$9,520 | 2,413,637 | 2,115,915 |
| Special events | 820,322 | 1,178,344 | | 1,998,666 | 1,891,300 |
| Investment income | 167,716 | | | 167,716 | 126,681 |
| Other revenue | 57,427 | | | 57,427 | 71,529 |
| Net assets released from restrictions | 2,759,238 | (2,759,238) | | - | - |
| Total revenue | 8,529,458 | 332,361 | 9,520 | 8,871,339 | 8,543,996 |
| EXPENSES: | | | | | |
| Program: | | | | | |
| Information and referral centers | 2,454,438 | | | 2,454,438 | 2,561,270 |
| Research | 1,599,057 | | | 1,599,057 | 1,434,888 |
| Public and professional education | 2,312,059 | | | 2,312,059 | 2,308,370 |
| Total program services | 6,365,554 | - | - | 6,365,554 | 6,304,528 |
| Supporting Services: | | | | | |
| Administration | 864,546 | | | 864,546 | 1,013,773 |
| Fundraising | 1,839,160 | | | 1,839,160 | 1,814,490 |
| Total supporting services | 2,703,706 | - | - | 2,703,706 | 2,828,263 |
| TOTAL EXPENSES | 9,069,260 | - | - | 9,069,260 | 9,132,791 |
| (Decrease) Increase in net assets | (539,802) | 332,361 | 9,520 | (197,921) | (588,795) |
| Net assets, beginning of year | 2,723,339 | 4,063,381 | 163,410 | 6,950,130 | 7,538,925 |
| Net assets, end of year | \$2,183,537 | \$4,395,742 | \$172,930 | \$6,752,209 | \$6,950,130 |

STATEMENTS OF FINANCIAL POSITION AUGUST 31, 2013 AND 2012



| | 2013 | 2012 |
|---|---------------------|---------------------|
| ASSETS | | |
| Cash | \$ 4,622,796 | \$ 4,922,101 |
| Contributions receivable | 815,795 | 203,517 |
| Investments | 1,345,010 | 1,178,679 |
| Prepaid expenses and other assets | 114,934 | 15,935 |
| Property and equipment – net | 2,850,986 | 2,959,789 |
| Total Assets | \$ 9,749,521 | \$ 9,280,021 |
| LIABILITIES AND NET ASSETS | | |
| Liabilities accounts payable & accrued expenses | \$ 558,253 | \$ 352,741 |
| Grants payable | 2,354,810 | 1,893,082 |
| Annuities payable | 84,249 | 84,068 |
| Total Liabilities | \$ 2,997,312 | \$ 2,329,891 |
| Net Assets | | |
| Unrestricted | \$ 2,183,537 | \$ 2,723,339 |
| Temporarily restricted | 4,395,742 | 4,063,381 |
| Permanently restricted | 172,930 | 163,410 |
| Total Net Assets | \$ 6,752,209 | \$ 6,950,130 |
| TOTAL LIABILITIES AND NET ASSETS | \$ 9,749,521 | \$ 9,280,021 |



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IN THIS ISSUE

- APDA Commemorates April Parkinson's Awareness month
- Research Funding Update
- Expanded Medicare Entitlements for PD patients
- Public Service Announcement Campaign to be launched by APDA
- APDA 2013 Annual Report

EDUCATIONAL RESOURCES

APDA's website www.apdaparkinson.org is the source of many free educational and patient/caregiver support materials. A complete list of booklets, supplements and other publications is available. Most can be downloaded or can be ordered by writing to the national office, calling 800-223-2732 or faxing to 718-981-4399. Free subscriptions to a monthly online newsletter (Digital Digest), a private caregiving coordination service (Lotsa Helping Hands), and an "Ask the Doctor" service are also available.

APDA Information & Referral Centers are the regional patient/caregiver resources for educational materials, physician and social services referrals, support groups, and programs.

A network list by state is available on the website.

APDA's National Young Onset Center – www.youngparkinsons.org, 888-223-3801, apda@youngparkinsons.org, addresses the unique challenges to young people with PD and their families.

APDA's National Resource Center for Rehabilitation – 888-606-1688, rehab@bu.edu, provides direct access to a licensed physical therapist for questions about exercise, information about programs in the caller's area and educational materials.

APDA's National Veterans Center – 888-838-6256 ext. 1715, susan.gulas@va.gov, assists active and retired members of the U.S. armed forces with PD and their families.

