



## What's Happening at APDA



- This past April, which was Parkinson's Awareness Month, APDA launched 30 Days, 30 Ways to raise critical funds and awareness for people with Parkinson's disease. We'd like to send a big thank you to all of our supporters for making this such a great success. Whether you gave a gift, spread the word via social media, or participated in one of our Optimism events — your support means the world to people living with Parkinson's disease.
- Did you know that every nine minutes another man or woman is diagnosed with Parkinson's disease? APDA recently created an engaging "Every Nine Minutes" infographic to share the facts about PD. To download the infographic, visit [apdaparkinson.org/pd-awareness-info-graphic](http://apdaparkinson.org/pd-awareness-info-graphic).
- On April 25th, APDA participated in the 21st Parkinson's Unity Walk in New York City. This extremely important event helps raise awareness and funds for research to find a cure for Parkinson's disease.
- APDA joined as the official charity of the Rite Aid Cleveland Marathon Walk Division, which was held on May 16th and May 17th. Rite Aid Cleveland Marathon Executive Director Jack Staph said, "APDA has made a tremendous difference in many lives through its outreach and research. My father had Parkinson's disease, and I have a close friend who is living with the disease as well. I've seen its effects first-hand, and I'm proud that we can bring APDA to Cleveland to help raise money to benefit those coping with Parkinson's disease."

## Ways to Support APDA

There are so many ways you can support the American Parkinson Disease Association and the people we proudly serve. It's only because of generous donors like you that we can continue to *Ease the Burden — Find the Cure* for Parkinson's disease. No matter how you choose to support APDA — every dollar makes a huge impact on those who turn to us for help.

- **Tax-deductible donation by mail or online** — your gift helps fund vital support and services while advancing research to find a cure.
- **Memorial and tribute giving** — a thoughtful way to honor a loved one or dear friend while at the same time giving hope and optimism to others.
- **Become a monthly supporter** — your reoccurring gift ensures stable funding throughout the year.
- **Name APDA in your will** — one of the simplest and most effective planned gifts is a bequest, or a gift made by a clause in your will.
- **Matching gifts** — double the impact of your gift by asking your employer to match your contribution to APDA.
- **Birthday or anniversary fundraiser** — ask your friends and family to support APDA in lieu of gifts.



# INSIGHTS

SPRING 2015  
NEWSLETTER

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135 Parkinson Ave.  
Staten Island, NY 10305  
(800) 223-2732

[apda@apdaparkinson.org](mailto:apda@apdaparkinson.org)  
[www.apdaparkinson.org](http://www.apdaparkinson.org)

**Chairman of the Board of Directors**  
Fred Greene

**Chairman of the Scientific Advisory Board**  
David G. Standaert, MD, PhD

**President & CEO**  
Leslie A. Chambers

## FDA Approves Two New Revolutionary Parkinson's Medications

The American Parkinson Disease Association (APDA) is excited to share that the U.S. Food and Drug Administration (FDA) has approved two new medications — RYTARY™ and DUOPA™ — as



Dr. David G. Standaert working in the lab

treatment for people with Parkinson's disease. Both of these therapies offer a better way to deliver carbidopa and levodopa medication — and therefore help control symptoms.

This is very exciting and hopeful news for the more than one million people living with Parkinson's disease. Dr. David G. Standaert, Chairman of APDA's Scientific Advisory Board says, "These are two very exciting new treatments which offer new opportunities to patients at different stages of their disease and help to better control their symptoms."

### Key highlights about RYTARY™

RYTARY™ is an extended release formulation of carbidopa and levodopa and is manufactured by Impax Pharmaceuticals. RYTARY™ is designed to address one of the most significant unmet needs for people living with Parkinson's disease, which is to reduce the amount of time during the day when their symptoms are not adequately controlled.

People who take carbidopa and levodopa may find that over time that the drug becomes less effective and may experience a worsening of symptoms as the drug ceases to work successfully. As RYTARY™ is developed to

release more slowly over time it will maintain the levodopa levels and will provide greater treatment stability. This treatment will help those in the middle stages of Parkinson's disease who have problems with the effects of their medication wearing off.

### Key highlights about DUOPA™

Developed by AbbVie, DUOPA™ is a new approach to the delivery of carbidopa and levodopa for the treatment of the motor symptoms of Parkinson's disease. It is administered using a small, portable infusion pump that delivers carbidopa and levodopa directly into the small intestine.

DUOPA™ is the first and only treatment providing 16 continuous hours of carbidopa and levodopa for motor fluctuations in advanced Parkinson's disease. In a clinical trial, patients treated with DUOPA™ experienced significantly greater improvement in symptom control than patients treated with oral carbidopa and levodopa immediate release tablets.

This treatment will help those in the advanced stages of Parkinson's disease who cannot manage symptoms with regular tablets and other oral medications.

APDA's commitment to supporting clinical trials and improving outcomes is critical to our mission. We are honored that researchers funded by APDA participated in conducting the clinical trials that were critical in the FDA's decision to approve these important new treatment options. This work is only possible because of our generous donors who have continued to partner with APDA to make a profound difference.

To learn about all the ways you can support APDA, please call (800) 223-2732 or visit [www.apdaparkinson.org/ways-to-donate](http://www.apdaparkinson.org/ways-to-donate).

For more information, visit our website at [www.apdaparkinson.org](http://www.apdaparkinson.org), or call (800) 223-2732. To make a donation online, visit [www.apdaparkinson.org/SpringInsights](http://www.apdaparkinson.org/SpringInsights).



A message from  
President and CEO,  
Leslie A. Chambers

Dear Friends,

Leadership is more than a position or a title. It's a responsibility. It's a talent. It's a commitment to progress and innovation. It's pushing boundaries and choosing to lead in a way that positively impacts others.

I believe we are all leaders in the fight against Parkinson's disease. As a supporter of the American Parkinson Disease Association, you are a critical part of our ability to help people battling Parkinson's disease. You are also an essential driver in accelerating research to find a cure.

Since our founding in 1961, APDA has raised and invested more than \$86 million in patient services and education and has been a funding partner in most of the major Parkinson's disease scientific breakthroughs. You make all of this possible.

Our organization is made up of many layers of courageous and passionate leaders who are all working towards our dual purpose: to *Ease the Burden* — *Find the Cure* for Parkinson's disease.

We are so grateful for our volunteers who work tirelessly to provide the day-to-day grassroots support, which is the backbone of APDA. Additionally, we take great pride in our Scientific Advisory Board that is made up of some of the world's top clinicians and researchers who are committed to funding the most promising scientific discoveries in Parkinson's disease. And our National leaders are focused on delivering innovative signature programs and services to all impacted by Parkinson's across the disease continuum.

Our volunteer and staff leadership is stronger than ever. I am confident that together we will keep moving forward to provide the best possible support to those battling Parkinson's disease. We will keep pushing forward until we find a cure.

Looking forward to the future,

Leslie A. Chambers  
President and CEO  
American Parkinson Disease Association

## APDA Commends New Co-Pay Program for People with Parkinson's



Did you know that medications for a person with Parkinson's disease cost an average of \$2,500 per year? Or, that surgery can cost up to \$100,000 per patient?

These expenses place a huge financial burden on people living with Parkinson's disease as

well as their families. But, we are excited to share some great news with you.

The Patient Access Network Foundation announced a new co-pay program for people living with Parkinson's disease. Established in February, this new co-pay program provides direct financial assistance to qualified patients, assisting them with prescription medication co-payments their insurance requires relative to their diagnosis.

*"The Patient Access Network Foundation recently launched a Parkinson's disease fund to assist patients with Parkinson's who are struggling to pay for the out-of-pocket cost of their prescription medications. In this way, the Patient Access Network Foundation hopes to improve the health and quality of life for many people living with Parkinson's,"* said Daniel Klein, President and CEO of the Patient Access Network Foundation.

Patients who qualify for the Patient Access Network Foundation's co-pay program are eligible to receive up to \$16,500 per year to cover costs associated with their medications. To qualify, applicants need to have insurance that covers the medication for which they seek assistance; they need to reside and receive treatment in the United States; and need to have a household income less than or equal to 500 percent of the Federal Poverty Level.

APDA Vice President of Programs and Services Robin Kornhaber believes that this very important program will help reduce financial barriers to treatment for people living with Parkinson's disease. *"The American Parkinson Disease Association commends the Patient Access Network Foundation for launching a financial assistance program to make critical medications more widely accessible for people living with Parkinson's disease,"* said Robin.

**To find out if you are eligible for financial reimbursement, please contact the Patient Access Network Foundation by phone at (866) 316-7263 or visit [www.PANfoundation.com](http://www.PANfoundation.com).**

## Live with OPTIMISM: Words of Wisdom

Every day, the American Parkinson Disease Association is inspired and empowered by all the incredible stories we receive from people living with Parkinson's disease, their care partners, and their friends and family.

Whether it's through a support group, a hobby like singing or exercising, or even just spending time with loved ones — every person finds hope and optimism in their own unique way.



**Barry, friend of Drew who is living with Parkinson's**

In 2013, Barry's longtime college friend, Drew, told him that he had been diagnosed with Early Onset Parkinson's disease. At the time, Drew had been living with the disease for five years and over that period the symptoms had slowly progressed. *"When I heard about Drew's illness, I wanted to help,"* said Barry. *"I decided to raise money for Parkinson's disease research by dedicating an Ironman 70.3 race in support of his fight against the disease."*

In the end, Barry was able to raise nearly \$2,800 with the support of family, friends and his company's matching contribution. *"It was a difficult journey, but definitely worth it to help a friend,"* he said.



**Alan, diagnosed with Parkinson's at age 74**

When Alan was diagnosed with Parkinson's disease, he decided to live life one day at a time and enjoy his wife, his family and whatever other joyful blessings came along. Music has always been Alan's favorite pastime and when he heard about the "Tremble Clefs," a music therapy choir for people with Parkinson's disease and their care partners, he and his wife joined. It has been an important source of support, fun and friendships.

Alan also enjoys making slideshows of family photos. It allows him to convey in the most meaningful way, what each family member means to him. *"Alan sees the light side of life in most situations and his unexpected, humorous quips often fill his space with the appreciative laughter of those around him. Yes, it is laughter and love that sustain him,"* says Jacqueline, Alan's wife and care partner.



**Lynda, wife and care partner of Bob who is living with Parkinson's**

Lynda's husband Bob was a renowned cardiologist and a respected professor of medicine when he was diagnosed with Parkinson's. He was only 45. At first, their lives were turned upside down, but they chose to live with hope and optimism. Lynda goes to APDA support groups while Bob attends exercise classes at their local Chapter. *"The support groups at APDA are a huge comfort and help. I've learned so much,"* she says.

Today, Lynda and Bob still enjoy travel and each other. Their lives have changed, but they've never given up. *"I cannot imagine what our lives would be like without the many services and support provided by APDA. They have been an absolute godsend,"* she says.

*Share your story and spread optimism!*

**Your words will let others know that they are not alone, provide a sense of hope and encouragement, and inspire people to live with optimism — no matter what they're going through.**

**Visit [apdaoptimism.org/inspire-others](http://apdaoptimism.org/inspire-others) to share your story.**