

What's Happening at APDA

- APDA is pleased to announce that we are a Bronze Sponsor of the 2016 World Parkinson Conference to be held September 20–23, 2016 in Portland, Oregon.
- APDA has joined the Parkinson's Action Network (PAN) Unified Partners Program, which strengthens our voice for better treatments and a cure for Parkinson's disease.
- APDA is a National Participating Partner with **Partners In Parkinson's**. We invite you and your family to attend an upcoming event. Milwaukee, October 10; St. Louis, October 31; Edison, New Jersey, December 5. Please visit www.apdaparkinson.org/partners-in-parkinsons/ for more information.

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.

- 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.

Ask the Doctor



Oren Levy, MD, PhD

QUESTION: I have been diagnosed with atypical Parkinson's disease. What is it and how does it differ from regular Parkinson's disease?

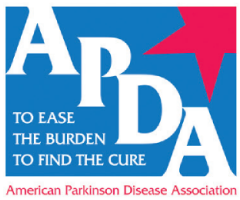
Today's answer comes from Oren Levy, MD, PhD and Winifred Mercer Pitkin, M.D., Assistant Professor; Division of Movement Disorders, Department of Neurology, Columbia University School of Medicine. Dr. Levy was also awarded one of APDA's 2015-2016 research grants.

Parkinsonism is a term that describes a group of symptoms including resting tremor, stiffness, and slowness. This group of symptoms reflects a problem with a part of the brain called the basal ganglia. Parkinsonism can be caused by many different diseases — the most common of which is Parkinson's disease. However, there are other diseases that can also lead to parkinsonism.

Since these diseases mimic Parkinson's disease, they are referred to as atypical Parkinson's disease. Usually, this designation refers to other neurodegenerative diseases, such as progressive supranuclear palsy (PSP), multiple system atrophy (MSA), or corticobasal degeneration (CBD). Sometimes, atypical Parkinson's disease can refer to non-degenerative causes of parkinsonism, such as multiple strokes.

As a general rule, dopamine replacement therapy (e.g., Sinemet) does not work as well for the causes of atypical Parkinson's disease compared to "typical" Parkinson's. Also, depending upon the specific cause, atypical Parkinson's disease leads to unique problems (e.g. low blood pressure, myoclonus) that are uncommon in those with typical Parkinson's, and require different treatments.

If you have your own questions for the doctor, please go to www.apdaparkinson.org/ask-the-doctor



INSIGHTS

FALL 2015
NEWSLETTER

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American Parkinson Disease Association is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code.

Funding the future of Parkinson's disease research

Thanks to friends like you, the American Parkinson Disease Association (APDA) is pleased to award \$1.3 million for 2015-2016 research funding to support four Post-Doctoral Fellowships, eight Research Grants to junior investigators, three Summer Student Fellows and eight APDA Centers of Advanced Research.

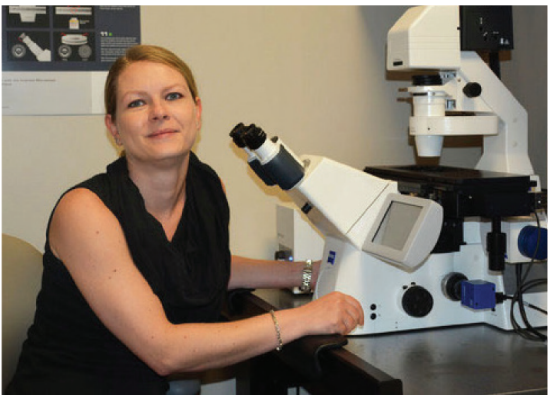
Furthering the most promising research

APDA's Scientific Advisory Board (SAB) — comprised of top scientists with Parkinson's disease (PD) expertise — reviews all research applications and recommends funding the most promising ones. From the potential research impact to the time period for completion, a variety of factors are taken into consideration. At the end of the process, 15 individual scientists and eight medical centers were awarded research funding.

"What sets APDA funding apart is its track record of launching the careers of the best and brightest scientists working on Parkinson's disease. This research enables the exploration of new ideas and conceivably holds the key to therapeutic interventions, prevention, treatments and the cure," commented SAB Chairman, David G. Standaert, MD, PhD, John N. Whitaker Professor and Chair of Neurology and Director, Division of Movement Disorders at the University of Alabama at Birmingham.

Funding scientific discoveries

Each and every one of these researchers could hold the key to better treatments — and even a cure — for Parkinson's disease. That's why we've been committed to investing in research since our organization was founded. In fact, APDA has been a funding partner in most

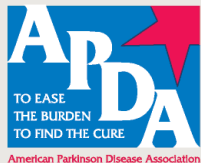


2015-16 APDA grant recipient Fabienne C. Fiesel is conducting Parkinson's disease research.

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
- The research at Robert Wood Johnson Medical Center, which led to the discovery of a mutation in the gene alpha-Synuclein, named PARK1

"In its relentless pursuit to Find a Cure, APDA pledges to continue to fund research initiatives to meet the collective goal of one day putting an end to this devastating neurological movement disorder that affects more than one million Americans," said Leslie A. Chambers, APDA President & CEO.



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

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



A message from
President and CEO,
Leslie A. Chambers

Dear Friends,

What will tomorrow hold for Parkinson's disease research? Every day, your support enables us to fund the researchers, scientists, and physicians who hold the keys to better treating and even curing Parkinson's disease.

In particular, you help us encourage young researchers to devote their entire careers to exploring Parkinson's disease. Programs like our Post-Doctoral Fellowships, Research Grants, and Summer Student Fellowships allow us to invest in the research of these promising, young scientists.

In addition, APDA's Dr. George C. Cotzias Memorial Fellowship assists young neurologists in establishing careers in Parkinson's disease research, teaching and patient service. Many of the winners of this prestigious fellowship — such as Dr. Standaert and Dr. Scherzer — go on to join our Scientific Advisory Board and play a pivotal role in developing treatments for Parkinson's.

We also help fund established researchers who are exploring innovative ideas. By doing so, they can present their findings to the National Institutes of Health, which can yield additional funding and multi-year grants.

I can't emphasize enough how important your support of APDA is to Parkinson's research. With your help, we're ensuring the finest scientific minds are focused on our top priority: Finding a cure for Parkinson's disease.

Looking forward to the future,

Leslie A. Chambers
President and CEO
American Parkinson Disease Association

Meet Eszter,

a young mother with
Parkinson's disease



Eszter was diagnosed with PD at age 11.

Many people are diagnosed with Parkinson's disease later in life. But for some individuals — like 33-year-old Eszter — Parkinson's disease strikes far earlier.

Born in Budapest, Hungary, Eszter was diagnosed with Parkinson's disease at just 11 years old. It began with shaking in her right hand when she played the guitar, wrote, or performed other small movements.

“It came slowly. As I was so young, my parents handled it very well,” says Eszter. “I just grew to accept it as part of my life.”

Learning to cope with Parkinson's disease

Eszter's first neurologist put her on medication; however, it did not make a significant impact. Because her symptoms were so mild, her doctor discontinued her medication after a year.

She spent her childhood playing sports and horseback riding, which she credits with slowing the progression of her Parkinson's disease symptoms. To cope with the tremors in her right hand, Eszter learned to write with her left.

Now that her disease has progressed, she avoids writing but can still type. Instead of doing a lot of walking on streets and other flat surfaces, she prefers running in the forest. Eszter is also talking to doctors about resuming medication to treat her Parkinson's disease.

Living optimistically

Today, Eszter is married and has two-year-old twin boys. She's also working successfully in the field of economics and international relations. Sharing her positive outlook on life, Eszter advises people who are newly diagnosed to “*Know your needs, gather information, and map your possibilities!*”

Looking for young onset Parkinson's disease resources?

Visit apdaparkinson.org/resources-support/national-young-onset-center for information about young onset support groups, podcasts, publications and more.

Interview with Jon Palfreman, Author of Brain Storms: *The Race to Unlock the Mysteries of Parkinson's Disease*



In 2011, Jon Palfreman was diagnosed with PD, which inspired him to write a book about his journey.



Thirty years ago, television producer Jon Palfreman created a well-renowned documentary called “The Case of the Frozen Addict.” In the documentary, he profiled a group of young drug addicts who appeared to come down with the symptoms of Parkinson's disease because they had taken a bad version of a synthetic drug.

In 2011, Palfreman was diagnosed with Parkinson's disease himself, which inspired him to write a book — *Brain Storms: The Race to Unlock the Mysteries of Parkinson's Disease* — which was published on September 15, 2015. We sat down with Palfreman to find out more about his research and his personal experience with Parkinson's disease.



with Jon Palfreman

Q. Tell us about your new book.

A. The book was my journey as a journalist and as a patient to find out as much as I could about Parkinson's disease — and share it with the community. It's been a privilege to meet such courageous, insightful and clever patients as well as some brilliant researchers.

“You've got to seek a positive outlook, and you need to seek out other people with Parkinson's disease because they're an amazing source of advice.”

Q. How did you first get into writing?

A. I'm really a documentary producer. I worked at the BBC in England. In 1985, I came over to the U.S. to make an episode of the TV series *NOVA*, which was what led me to the story on Parkinson's disease. For most of my career I've been a science journalist working for *NOVA* and *Frontline* and other long form documentaries. I'd make stories about everything from climate change to genetically modified foods to healthcare. I've also over the years written three books. And this past one is the one I'm most proud of.

Q. What symptoms did you notice before you were diagnosed with Parkinson's disease?

A. In retrospect, they are sort of obvious. In my case, it was a tremor in the left hand. You notice the little things like not swinging your arms when you walk. Like many people, when I got the diagnosis I wasn't totally convinced. I went through the stages of grief and I was in denial for a bit. It took me a full year before I was ready to accept this and do something constructive about it.

Q. In what ways do you seek support?

A. While it's generally slowly progressing, it's a tough disease to live with. The great thing is that there is an extraordinary community of people who have it — who are very sharing and very supportive — and also a great community of researchers. It's not hard to get help and to get good advice.

Q. What would you say to donors who are considering giving to APDA?

A. We know more about the human brain now than we've ever known. It's an exciting time when giving money for research is likely to pay off.

Q. What's your advice to other people living with Parkinson's disease?

A. You've got to seek a positive outlook, and you need to seek out other people with Parkinson's disease because they're an amazing source of advice. The great thing about Parkinson's disease is that you can live a long and very good life. The second thing is the value of exercise. Keeping fit and exercising is a tremendous benefit. It's within every Parkinson's disease patient's hands to make the most of it.

To get your copy of *Brain Storms*, please visit apdaparkinson.org/Brainstorms