



# THE PARKINSON'S AND MOVEMENT DISORDER FOUNDATION

Newsletter  Winter 2018

## 2018 PMDF Fundraiser

by Tien Nguyen



This year's fundraiser, The Parkinson's and Movement Disorder Foundation Presents: Taste of Vietnam, was held right in the heart of Little Saigon at Grand Garden Restaurant in Westminster, California. The setup of the venue blended beautifully with the Vietnamese inspired theme, with the abundance of lanterns, flowers, and chandeliers providing an engaging atmosphere for all of the attendees.

Hosted by MC Leena Nguyen, the event had a great turn out with over 120 people in attendance. Events of the night included raffle prizes, live entertainment, seven course dinner and the highly-anticipated silent auction featuring items ranging from all-inclusive stays in the Caribbean islands to a professional photoshoot and luxury hotel stay worth \$5,500. Our live entertainment for the night featured a dragon and drumming performance, traditional Vietnamese dances, and martial arts performance. DJ Free Willy provided music for attendees to dance the night away. The Taste of Vietnam event was full of entertaining events for the whole family. We hope everyone had a memorable night.

The Parkinson's and Movement Disorder Foundation would like to thank everyone who attended the Taste of Vietnam Fund-

raiser and/or donated to the event. We would also like to give special thanks to all the companies who donated auction items for our silent auction. We greatly appreciate our major sponsors US World Meds and Lundbeck. All proceeds from the event will go toward funding research projects for movement disorders.

This fundraiser would not have been possible without the support of the PMDF board members, and the volunteers: Karen, Judy, Spencer, and Roger from the Parkinson's and Movement Disorder Institute, along with Jennifer Braganza and Heather Nguyen, for helping with the entire event. We would also like to thank Duc Dang's Tae-Kwon-Do for taking the time to volunteer their efforts to close out our live entertainment, demonstrating their variety of martial arts performances.

Over the years PMDF has donated \$315,000 to research and projects. We hope to donate much more in the future with your support. Again, thank you to everyone who participated in the 2018 fundraiser to help raise money for research in Parkinson's disease and movement disorders.



### The Parkinson's and Movement Disorder Foundation

14772 Moran Street  
Westminster, CA 92683  
(714) 369-7426  
www.pmdf.org

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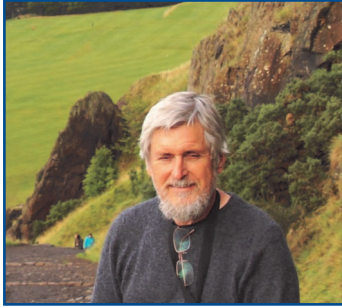
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## President's Letter



Dear friends of PMDF,

Our recent fundraiser was a great success. It was a very enjoyable event, and it raised a record amount of money for our research program. You can read about it elsewhere in this newsletter.

We received 33 grant proposals this year. The board narrowed it down to four, and we will decide which two we will fund within a week. As always, there were many good proposals that we would like to have been able to support.

Our main article in this newsletter talks about two new drugs to help with “off” periods in Parkinson’s disease. It’s exciting to see how treatment options keep improving.

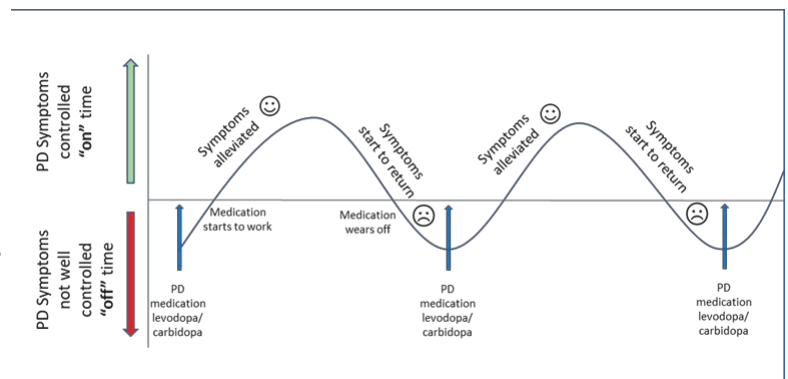
Thank you for your support.

Mark Wadsworth  
PMDF President

## New Medications for Parkinson’s Disease— Treatment of “Off” Episodes

by April Ingram

Many people with Parkinson’s disease are regularly prescribed levodopa/carbidopa, medications developed to help manage motor symptoms such as tremor or shaking, rigidity, diminished balance, and slowed movement. Although these medications are often effective, people frequently experience fluctuations in the presence and intensity of their symptoms as medication’s effects wear off. These fluctuations have been characterized as “on” time—when the medication is working and symptoms are minimal or absent, and “off” time—when the medication hasn’t yet taken effect or the effects have worn off and symptoms return. For many people, “off” times are quite predictable, often occurring right before the next dose of regular medication is due, but for others, “off” times can be unpredictable and occur rather suddenly. In 2017, the Parkinson’s Disease in America survey reported that half of survey respondents taking carbidopa/levodopa therapy experience “off” times, and most notice symptoms that seriously affect their daily activities. Despite symptoms lasting up to six hours for a quarter of people, 43% report that they don’t take any action to manage these “off” episodes. More information about the Parkinson’s Disease in America survey can be found at [Parkinsonsdisease.net](http://Parkinsonsdisease.net).



The first recommendation for individuals experiencing symptomatic “off” time is to speak with their doctor. Doctors may be able to adjust the type, timing, or dose of primary medication, or recommend an add-on medication. Add-on treatments are extra medications, taken in addition to an existing prescription.

Recently, the Food and Drug Administration (FDA) approved two new medications, specifically to be used as add-on treatments to levodopa/carbidopa to help people with Parkinson’s Disease who are experiencing “off” episodes.

The first add-on treatment is Xadago®(safinamide), prescribed as a tablet to be taken once daily, developed by Newron Pharmaceuticals, approved in the United States in March 2017. Xadago has been approved for use in Europe since 2015. This is exciting news, as there hasn’t been a new Parkinson’s drug approved by the FDA in more than a decade. The approval was based on data from two large clinical trials that showed that the drug produces significant increases in the duration of “on” time and decreased periods of “off” time. Xadago is not a medication that can be taken alone; it is for those people already taking levodopa/carbidopa and isn’t recommended for everyone. It is not advised for people with severe liver impairment, or anyone already taking other monoamine oxidase inhibitors, opioid drugs, St. John’s wort, certain antidepressants, cyclobenzaprine, or the cough and cold medicine dextromethorphan. The most common side effects reported with Xadago are dyskinesia, falls, nausea, and trouble sleeping.

Xadago works in two different ways. First it allows dopamine, a chemical in the brain, to work for longer periods of time, which is important because it is low levels of dopamine that are associated with Parkinson’s disease. Dopamine is required for proper motor control as it transmits signals in the brain that are involved in smooth, purposeful movements. The level and function of dopamine is increased by Xadago’s ability to inhibit an enzyme, monoamine oxidase B, from breaking down dopamine and also by blocking transporter molecules responsible for its uptake, or its absorption and retention. Also, Xadago prevents excessive release of the neurotransmitter glutamate, which is involved in nerve cell communications.

Another recently approved add-on treatment is Inbrija™, the first and only inhaled levodopa for intermittent, as-needed treatment of “off” episodes for people with Parkinson’s who are already taking levodopa/carbidopa. Inbrija works to ‘top up’ therapeutic levodopa levels between regular levodopa/carbidopa doses. It was developed by Acorda Therapeutics, Inc. and is expected to be available by prescription within the first few months of 2019.

This novel treatment and its inhalation delivery system is the culmination of decades of research, studying the molecules, the administration and clinical response, all beginning with the initial work of Dr. Robert Langer at Massachusetts Institute of Technology (MIT). The FDA based their approval of Inbrija on clinical studies including approximately 900 people with mild to moderate Parkinson’s disease who were receiving a levodopa/carbidopa regimen and experiencing “off” time. Individuals were not able to participate in the studies if they had asthma, chronic obstructive pulmonary disease (COPD), or any chronic lung disease. Study participants receiving Inbrija experienced a significant improvement in motor function after 12 weeks and notably, participants experienced an onset of action, meaning an improvement in “off” time symptoms, as quickly as 10 minutes after inhaling Inbrija. During the clinical studies, the most common side effects were cough, upper respiratory tract infection, nausea and discolored mucus. Inbrija cannot be used by people who are taking, or have taken, a nonselective monoamine oxidase inhibitor such as phenelzine or tranylcypromine within the last two weeks. The levodopa powder comes in a capsule, but the capsule cannot be taken orally, or broken apart, it can only be used with the inhaler provided.

Although research has confirmed the effectiveness of dopamine-based therapies (levodopa/carbidopa) throughout the course of Parkinson’s, it can be challenging to maintain dopamine levels in the brain in the ‘sweet spot’ zone where symptoms are adequately controlled without side effects. The recent approvals of add-on treatments Xadago and Inbrija are the result of years of research and deliver meaningful improvements and hope to people challenged by fluctuations in symptom control throughout their day.

As always, it is very important to work with your doctor to discuss your current medications and potential add-on treatment options to find a regimen that works best for you and your symptoms.

**We would like to thank the following companies for their contribution to the PMDF Fundraiser in 2018.**

**Abbott Laboratories**  
[www.abbott.com](http://www.abbott.com)

**Guy Harvey**  
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**Pho K-tea**  
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**Impax Laboratories**  
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**Katella Deli**  
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**Avanir Pharmaceuticals Inc.**  
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**Knott's Berry Farm**  
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**Six Flags Magic Mountain**  
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**Bravo Sports**  
[www.bravosportscorp.com](http://www.bravosportscorp.com)

**Malibu Wine Safari**  
[www.malibuwinesafari.com](http://www.malibuwinesafari.com)

**South Coast Botanic Garden**  
<https://southcoastbotanicgarden.org/>

**Curves**  
[www.curves.com](http://www.curves.com)

**Merz Pharma**  
<http://www.merzusa.com>

**Teva**  
[www.tevausa.com](http://www.tevausa.com)

**Davie's Vineyard**  
[www.daviesvineyards.com](http://www.daviesvineyards.com)

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**We would like to thank the following donors for their contribution to the PMDF Fundraisers in 2018.**

Advanced Cardiovascular Care  
Duc Dang's Karate  
Loan Dang  
E&S Hirsch Foundation  
Paul & Joyce Fujita  
Patrick Goode  
Heather Hall  
Bernie Hulse  
Gayle Knapp

Peter McRoskey  
Lydia McWeeney  
Tuyet Nguyen  
Vinh Nguyen, M.D.  
Mayank Pathak  
Kenneth Price  
James Ruetz  
Visage Communications, Inc.  
Deborah Wilson

# PMDF Fundraiser Photos



# MOVE4U 5K Walk/Run Fundraiser

**Mile Square Park  
Fountain Valley**

**Saturday, May 11, 2019**

**8:30 am: Sign-In**

**10:00 am: Race Start Time**

**11:00 am: Lunch Available**

**First Place Prize - TBA  
Second Place Prize - TBA  
Third Place Prize - TBA**

**Chance to win a prize in raffle drawing. Raffle prizes include: Katella Deli Gift Card, Amazon Gift Card, Starbucks Gift Card, iTunes Gift Card, Target Gift Card & More**

**\$20 – per person to register**

**\$5 – parking inside the park**

**Free – street parking**

**Lunch, T-shirt and beverages are provided for participants**

**Register online at: <http://www.pmdf.org/events.php>**

**We would like to thank the following corporations and people for their contribution to PMDF in 2018.**

These contributions were given to PMDF directly and not through a fundraising campaign.

Miriam Begg  
Boeing Company  
Dianne Brockway  
Kathleen Chovan  
FHC, Inc.  
Fountain Valley Central Pharmacy  
James Fujimoto  
Paul & Joyce Fujita  
Laura Gasser  
Jonady Hom Sun in memory of John Hom

Larry Lee  
Eugene Massey  
Joseph Nardacci, Jr.  
One Hope Foundation  
Pledgeling Foundation  
Kemal Serdengecti  
Marilyn Silverstein  
Deborah Wilson

**5K Run/Walk  
Saturday  
May 11, 2019  
8:30 a.m.**

**Movement Disorders**

**MOVE4U 5k**

**Mail-in registrations  
must be postmarked  
by May 3, 2019**

**Registration Form**

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

EMAIL: \_\_\_\_\_ PHONE: \_\_\_\_\_

5K T-SHIRT SIZE (Circle One) Adult: S      M      L      XL      Minimum age of entry 13

**IN CASE OF RAIN:** The race will proceed as planned. We reserve the right to change the date under extreme circumstances.

**ADDITIONAL DONATIONS**

Donations are tax-deductible and an acknowledgement letter will be sent to the donor for tax purposes

Contributor Information			
First Name	Last Name	Mailing Address	Amount

**ENTRY FEE(S) OR DONATION**

Entry Fee:                      \$ \_\_\_\_\_ (\$20)

Donation:                        \$ \_\_\_\_\_

Total:                            \$ \_\_\_\_\_

My Employer has a  
Matching Gift Program: \$ \_\_\_\_\_

Please make check payable to **PMDF**

Visa ( )    MasterCard ( )

\_\_\_\_\_  
Credit Card No.

\_\_\_\_\_  
Expiration Date

\_\_\_\_\_  
CVV Code (last 3 digit on the back of your card)

Mail Entry Form & Payment to:

PMDF  
14772 Moran St.  
Westminster, CA 92683  
For more information call: 714-369-7426

**RELEASE FORM** (all registrations must be signed)

I hereby waive any and all claims against PMDF, event sponsors, personnel, and all other persons, firms, corporations and/or entities or anyone associated with this event, their respective or successors, for any injury or claims for damages that I may suffer from participation in this event. I grant full permission for organizers to use photographs, videotapes, recordings or any other record for this event.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of parent or guardian (if under 18 years old)

\_\_\_\_\_  
Date



THE PARKINSON'S AND MOVEMENT DISORDER FOUNDATION

14772 Moran Street  
Westminster, CA 92683

[www.pmdf.org](http://www.pmdf.org)

## **OUR MISSION**

To support basic and clinical research into the causes, treatments and cures for Parkinson's disease and other movement disorders such as dystonia, myoclonus, spasticity, and tremor.

The Parkinson's and Movement Disorder Foundation is committed to working with other organizations that have similar philosophies in an effort to bring together expertise from both basic and clinical science perspectives.

We are dedicated to enhancing the quality of life for those who suffer from movement disorders and their families, through research, education, and community outreach.