



THE PARKINSON'S AND MOVEMENT DISORDER FOUNDATION

Newsletter  Fall 2018

PMDF Presents: Taste of Vietnam

by Tien Nguyen

The fall season is here, which not only brings us changes in the weather, but also a reminder that our annual end of the year event is soon approaching! This year, the event was chosen to be held right in the heart of Little Saigon, an area known to many as a community where much of the Vietnamese culture is embraced and exemplified during the times of traditional holidays and cultural festivities.

The Parkinson's and Movement Disorder Presents: Taste of Vietnam will be held on Saturday, November 17, 2018 from 5:00 PM to 9:00 PM at Grand Garden Restaurant in Westminster, California. In addition to coming out on a night to support funding on scientific research on Parkinson's disease and other movement disorders such as spasticity and dystonia, there will be dinner, raffle prizes, and of course, our always popular silent auction.

Check in starts right at 5:00 PM, and the silent auction opening up for bidding at that time. The earlier you arrive, the more time you will have to mingle with fellow supporters of our cause, as well as having a better chance to scope out the auction items ahead of your competition! This year, we have items ranging from an exciting Giraffe and Wine Tasting Tour, Disneyland Park hopper tickets, to Resort Accommodation Certificates to islands in Antigua, Grenadines, and Barbados. Please refer to (page) to see just a sneak peak at the auction items we have to offer for our silent auction.

Welcoming remarks will be made by Dr. Daniel Truong as well as our newest additions to the Parkinson's and Movement Disorder Foundation board, including medical advisor, Dr. Kong Truong and pharmaceutical advisor, Jenny Dang. During the

course of dinner, live entertainment will be provided with a Dragon Dance & Drumming Performance by Thiên Ân Performing Arts, Traditional Vietnamese Dancing Performances by Lac Hong Performing Arts Group, and martial arts performance by Duc Dang's Tae-Kwon-Do.

Tickets are available for only \$80 per person, with discounts available for tables of 10 at \$750. All proceeds will go to supporting basic and clinical research into the causes, treatments, and cures for Parkinson's disease, dystonia, and other movement disorders. Enjoy a night of dinner and excitement in the season of giving as you embrace a taste of Vietnam while supporting a great cause. Reserve your seat today by filling out the registration form on page 8 or online at the PMDF website at <http://www.pmdf.org/events.php> Follow us on Facebook at www.facebook.com/thePMDF to find the latest news and updates for the upcoming event.

If you are unable to attend, please consider making a donation to the PMDF to help support research into Parkinson's and movement disorders. You can make donations by mailing in a check to the PMDF or by going to the following link online: <http://www.pmdf.org/support.php>



PMDF Pharmaceutical Advisor, Jenny Dang

The Parkinson's and Movement Disorder Foundation

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President's Letter



Dear friends of PMDF,

I'm excited about our fall fundraiser, *A Taste of Vietnam*. We've arranged for great food and entertainment, and we've made the event more accessible by scheduling it on a Saturday night (November 17) and lowering the price. I'm looking forward to a memorable evening and a huge infusion of cash to support our research program. See the article on page 1 for details.

Also in this issue, you can read about one of the research programs we have sponsored on page 3, and there's an article about Lewy body dementia, a condition closely related to Parkinson's disease.

In the last newsletter, my wife and I were about to brave the heat and humidity for four days in Washington, DC. I am happy to report that we had a great time. The heat and humidity were not bad, and we even got a bit of refreshing rain. We rode the Metro a bit, but mostly we walked, to museums, monuments, restaurants, the zoo, and a concert by the Eagles. There is much more to see and do there than we had time for; we saved something for next time.

Order those fundraising tickets, and I'll see you there!

Mark Wadsworth
PMDF President

Sincerely,

A handwritten signature of Mark Wadsworth in cursive script.

Mark Wadsworth
PMDF President

PMDF Grant Award Winner Prof. Salvatore Valiante Explores Nanotechnology

by Mary Ann Chapman, PhD



Prof. Salvatore Valiante

Our brains are the master controllers of our bodies and are responsible for every thought, plan, and emotion we've ever had. Given their importance, it's not surprising that our brains are protected by barriers that are difficult to penetrate. Mostly, this is a good thing. However, when brain systems go awry, as they do in Parkinson's disease, dystonias, and selected other movement disorders, these barriers make it difficult to get needed treatments to their targets.

Enter nanotechnology. Nanotechnology basically refers to manipulating things on a very tiny scale, such as atoms or molecules, whose size is measured in nanometers (one human hair has a width of about 75,000 nanometers). Our 2018 PMDF grant winner Prof. Salvatore Valiante is working on a "nano" delivery system designed to carry treatments across the barrier that surrounds the brain. I spoke with Prof. Valiante via e-mail to find out more about his work.

Can you explain your current research?

My research team focuses on delivering drugs across the brain's biological defence known as the blood brain barrier. We developed a nanodelivery system that acts as a protective shell to help transport molecules across the blood brain barrier. We are currently testing the ability of this system to transport physiological substances (neuropeptides) that, in the laboratory, reduce damage to dopaminergic neurons—the cells that degenerate and die in Parkinson's disease. We wonder whether our delivery

system, filled with neuropeptides, can help dopaminergic neurons recover from damage.

What aspect of your research are you most excited about?

We previously investigated the chemical and safety properties of our nanodelivery system, which led to exciting results that were published in international journals. Although there is still much work to do, several aspects are particularly exciting:

From both scientific and humanistic aspects, it is amazing (and a great responsibility) to participate in the world's efforts to understand the physiology and pathology of movement disorders, possibly helping to mitigate the disease's effects.

From the technical point of view, we are now trying a new 3-dimensional cell culture model to better mimic the actual condition of the diseased brain. This could improve our ability to determine whether the molecules we are testing effectively reduce damage to dopaminergic neurons.

What are the major challenges in movement disorder research?

Scientific research moves along in different, complementary ways. In movement disorder research there is a branch that aims to clarify mechanisms of disease, another branch that tries to improve early diagnosis, and another that aims to ameliorate symptoms and improve patients' lives. Each is a major challenge that must be faced, contributing to the main goal of preventing or delaying onset of movement disorders. This can be achieved only if these branches cooperate to share large amounts of information.

Anything else you'd like our readers to know?

I'd like to thank the patients with movement disorders and their families who are mandatory for scientific research advances in this field. I'd like to show my gratitude to PMDF for its remarkable support in our research, hoping to move movement disorders a little step forward toward a cure.

Medial Mogul Ted Turner Diagnosed With Lewy Body Dementia

By April Ingram

For decades, the world has recognized entrepreneur Ted Turner as leader of the business world, a pioneer of television broadcasting, and an unprecedented philanthropist. This September, in an interview on CBS Sunday Morning, Turner revealed that he has been diagnosed with Lewy body dementia.

Although Lewy body dementia is the second most common progressive dementia after Alzheimer's, awareness of the condition is quite low. Lewy body dementia shares some symptoms with Alzheimer's and some with Parkinson's disease. The symptoms of dementia, which resemble those of Alzheimer's, include problems with memory, thinking, and the ability to engage in daily activities. Symptoms that resemble those of Parkinson's include rigidity, tremor, and slowness of movement. Dizziness, sleep difficulties, lack of motivation, and depression may also be present.

One of the most distinctive features of Lewy body disease is the presence of highly detailed visual hallucinations (seeing things that aren't there). These hallucinations typically occur early in course of disease. Hallucinations may also affect the other sensory systems, such that people may hear sounds that aren't there, or may smell, taste, or feel things that aren't there. Another distinction of Lewy body disease is that attention, alertness, and wakefulness often fluctuate moment to moment or day to day. For example, the person may converse normally one day and be more confused the next day.

Lewy body dementia can be very difficult to diagnose because there is no single test, such as a blood test or brain scan, and many of the features and symptoms resemble other diseases. Receiving a diagnosis of Lewy body dementia typically takes three or more doctors over a period of 12 to 18 months. The following table lists the most recent diagnostic criteria developed by neurologists around the world. These features strongly suggest that someone has Lewy body dementia. For the

full article, published in the journal *Neurology*, see the link at the bottom of the table.

Often, a variety of medical, neurological, and neuropsychological tests are used to identify the features of Lewy body dementia and to rule out other or confirm other possible causes of dementia, motor, or behavioral symptoms. Brain scans using SPECT or PET technology can help detect differences between Lewy body dementia and Alzheimer's disease. Sleep studies at specialized clinics can confirm REM sleep behavior disorder, and special cardiac imaging can detect changes in cardiac nerves associated with Lewy body dementia. Brain imaging (CT scan or MR imaging) can detect brain shrinkage and help rule out stroke, fluid on the brain (normal pressure hydrocephalus), or subdural hematoma. Blood and other tests might show vitamin B12 deficiency, thyroid problems, syphilis, HIV, or vascular disease. Depression is also a common cause of dementia-like symptoms.

Diagnostic Criteria for Lewy Body Dementia

Dementia (must be present for the diagnosis):
problems in thinking that interfere with everyday activities

Core clinical features (at least 2 must be present to indicate that the diagnosis is probably correct)

Unpredictable changes in thinking, attention, and alertness

Repeated visual hallucinations

REM sleep behavior disorder (person may act out dreams)

Parkinsonism, specifically slowed movements, tremor when limbs are at rest, and muscle rigidity

Adapted from McKeith et al, 2017. *Neurology*. <http://n.neurology.org/content/neurology/early/2017/06/07/WNL.0000000000004058.full.pdf>

The timing of symptom onset can also provide diagnostic clues. If cognitive symptoms appear before or within a year of motor symptoms, Lewy body dementia is more likely the cause than Parkinson’s disease. Signs of stroke or vascular dementia usually negate the likelihood of Lewy body dementia. Unfortunately, definitive diagnosis of Lewy body dementia can only be made by an autopsy after death.

Lewy body dementia usually occurs in older adults between 50–85 years old, is more likely to occur with advancing age, and affects slightly more men than women. As in Parkinson’s disease, some people diagnosed with Lewy body dementia have experienced symptoms of REM sleep behavior disorder for years or even decades earlier. In REM sleep behavior disorder, the muscle paralysis that normally occurs during REM sleep is incomplete or absent, and people may act out their dreams. Some cases of Lewy body dementia have appeared within families, but research has not shown a strong tendency for inheriting the disease. Studies are ongoing to reveal more information about causes and risks.

The progression of Lewy body dementia varies with each person and does not follow a set pattern of stages, as is seen in some other dementias. There is neither cure nor specific treatment to arrest the course of Lewy body dementia. While no medications are currently approved to specifically treat Lewy body dementia, those developed for other conditions can help reduce some of the symptoms. A comprehensive treatment plan can improve the quality of life for a people with Lewy body dementia and their caregivers. The average lifespan after onset is 5 to 7 years, and death usually occurs from pneumonia, complications of immobility, or other illnesses.

Even though Lewy bodies are found in brains of people with other diseases, there are three distinct changes that occur in brains of people with Lewy body dementia:

1. The brain’s cerebral cortex (outer layers of the brain) degenerates or shrinks. This brain tissue shrinkage (or atrophy) can affect reasoning and complex thinking, understanding personality, movement, speech, and language, sensory input, and visual perceptions of space.
2. Degeneration occurs in the limbic cortex, located at the center of the brain, which plays a key role in emotions and behavior.
3. Nerve cells die in the midbrain region. These nerve cells are involved in making the neurotransmitter (brain messenger) dopamine. People with Parkinson’s lose dopamine; in Alzheimer’s people lose the neurotransmitter acetylcholine. A person with Lewy body dementia loses both. The midbrain is involved in motor control, sleep/wake, arousal, sensory and autonomic functions (regulation of body functions such as heart rate, digestion, respiratory rate). This midbrain area also degenerates in Parkinson’s disease.

Important Information About Lewy Body Dementia

It is a relentlessly progressive disorder affecting thinking, movement, behavior and sleep.
It is not a rare disorder (affects about 1.4 million Americans).
It is the most misdiagnosed form of dementia (diagnosis typically takes 3 or more doctors over 12 to 18 months).
Early diagnosis is extremely important due to sensitivities to certain medications sometimes used in disorders that mimic Lewy body dementia.
It requires a high level of support, both for the person living with the disease and their caregivers.
<i>Adapted from the Lewy Body Dementia Association (Lewy body dementiaA)</i>

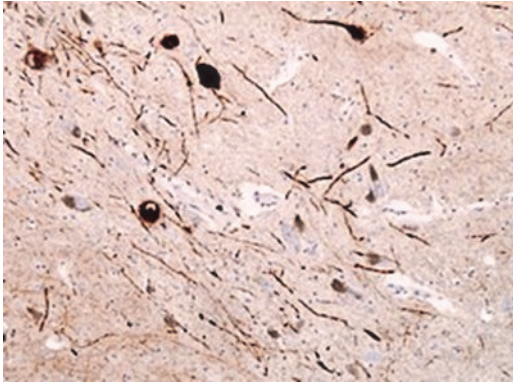
Treating Lewy body dementia and its symptoms can be challenging. Neuroleptic drugs (sometimes called psychotropic drugs) commonly prescribed to lessen the hallucinations, agitation, or restlessness often associated with dementia will induce or worsen Parkinson’s-like symptoms in some people with Lewy body dementia. Even though tremor is typically less pronounced in Lewy body dementia than in Parkinson’s, people with Lewy body dementia have a far less dramatic response to drugs such as levodopa that are used to treat Parkinson’s.

Continued on page 6

Medial Mogul Ted Turner Diagnosed With Lewy Body Dementia

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Protein clumps (indicated in brown) form in the brain in Lewy body dementia




By

Jensflorian [CC BY-SA 3.0 (<https://creativecommons.org/licenses/by-sa/3.0>) or GFDL (<http://www.gnu.org/copyleft/fdl.html>)], from Wikimedia Commons

Treating and caring for a person with Lewy body dementia requires frequent assessment and reassessment. Some people with Lewy body dementia can live at home with careful monitoring and supervision. Caregivers must learn to navigate and adapt to cognitive, behavioral, and motor changes. Attending support groups and learning skills in how to communicate with someone with dementia, as well as learning skills in helping someone with a motor disorder, will reduce caregiver stress and frustration. Caregiver resources can be found at the Lewy Body Dementia Association’s (Lewy body dementia) Research Centers of Excellence (RCOE), local and state offices on aging and health such as your Area Agency on Aging or the Alzheimer’s Association in your area.


Auction Items

Because of limited space we are not able to list all the auction items.



BRADFORD
Renaissance Portraits

Gift Certificate to Bradford Renaissance Portraits Studio + 1 night stay in Newport Beach



Elite Island Resorts
CARIBBEAN

8 Resort Accommodation Certificates to Caribbean Islands including Barbados, Antigua, Palm Island, and St. Lucia.



REMIX YOGA

3 Months of Unlimited Yoga



MODELONES Nail Art Tools Set With Shoulder Bag



malibu
WINE SAFARI
FAMILY-OWNED SINCE 1978

2 tickets to Giraffe and Wine Safari Tour



Disneyland
RESORT

2 Tickets to Disneyland



PALA
CASINO SPA RESORT

\$100 Dinner Credit to Bar Meets Grill



SAN DIEGO ZOO

2 tickets to San Diego Zoo or Safari Park



Knott's
BERRY FARM

4 tickets to Knott's Berry Farm

The Parkinson's and Movement Disorder Foundation Presents:

TASTE OF VIETNAM

RSVP by
November 2, 2018

DINNER • LIVE ENTERTAINMENT • SILENT AUCTION

SATURDAY, NOVEMBER 17, 2018

5:00 –9:00 PM

Grand Garden Restaurant

8894 Bolsa Ave. Westminster, CA 92683

\$80 per person

Half of your ticket is tax deductible

Reserve your seat by filling out the form below, or online at: www.pmdf.org/events.php

Registration Form

Name: _____

Address: _____

City: _____ State: _____ Zip : _____

Phone: _____ E-mail: _____

Yes, I/we will be attending *Taste of Vietnam* Fundraiser.

Enclosed is a check of \$ _____ for _____ tickets
Tickets for tables of 10 are available for \$750

Please charge to my credit card \$ _____ for _____ tickets

MasterCard Account Number: _____

Visa Expiration date: _____ CVV2 Code : _____
(last three digits in the back of your card)

I will not be able to attend, but would like to donate \$ _____
(your donation is tax-deductible)

Mail Registration Form & Payment to:

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THE PARKINSON'S AND MOVEMENT DISORDER FOUNDATION

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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.