



THE PARKINSON'S AND MOVEMENT DISORDER FOUNDATION

Newsletter  Spring 2018

The Parkinson's and Movement Disorder Foundation

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

Advisory Board

Mark Wadsworth
President

Mary Ann Chapman, Ph.D.
Vice President

Sami Nasrawi, PharmD
Secretary

Gianni Truong
Treasurer

Peter Perry
Deborah Wilson

Medical Advisors

Daniel Truong, M.D.
Victor Passy, M.D.
Kong Truong, M.D.

Pharmaceutical Advisor
Jenny Dang, PharmD

Advisor Emeritus

Jim Ruetz

Honorary Board Members

Tom Railsback
(Ret.) U.S. Congressman

Hon. Loretta Sanchez
U.S. Congresswoman

Victor Tsao

Executive Director

Tien Nguyen

MOVE4U 5k Walk/Run Fundraiser Event

by Tien Nguyen

With a new year upon us, a new name for the annual 5k walk/run event further aligned to the missions of the Parkinson's and Movement Disorder Foundation and the National Spasmodic Torticollis Association seemed appropriate. MOVE4U 5k will be held on Saturday, May 19, 2018 at Shelter #17 on Edinger Blvd.

This event is held annually in an effort to promote awareness, funds, and support towards research on Parkinson's disease and other movement disorders. This is a family-friendly event. Children ages 12 and below do not need to pay the registration fee.

We will have 1st, 2nd, and 3rd place prizes, with registered participants automatically entered in our raffle drawing. 1st place prize is 4 One-way Southwest E-tickets from Southwest Airlines (valued at \$800). 2nd prize is 4 Knott's Berry Farm tickets. 3rd place prize will be announced online under our Special Events page. Sign in for participants will begin at 8:30 AM. You can register online by visiting www.pmdf.org/events.php or by mail using the form on the last page in the newsletter.

Due to park regulations, registration cannot be processed at the park. Please register by May 15.

Special thanks to the following companies for their generous sponsorships: Karella Deli Bakery and Restaurant, One Pharmacy, Abbott Laboratories, Adamas Pharmaceuticals, Lundbeck, US WorldMeds, Pho K Tea, Teva Pharmaceutical Industries, and Neurocrine Pharmaceuticals.



What is MOVE4U 5k?

To move for U (you) is a motion to move for a cause and build awareness. You are not only moving to build awareness of the mission of our organizations, but for you—whatever personal circumstances have brought you to our fight against movement disorders.

Moving for the causes relative to our personal circumstances, we are brought together, united with others who believe in our cause. The overall unity at this event is accomplished year after year, in its continued success in building funds and awareness to overlooked movement disorders that have definitely deserved their time of acknowledgement.

President's Letter



Dear friends of PMDF,

As you can see in the article on Page 1, it's time once again for our annual 5K walk/run to fight Parkinson's disease and other movement disorders, now named MOVE4U. If you're a runner, it's a chance to compete and perhaps win a nice prize. If you're not a runner, the event will last long enough for you to complete the course walking, hopping, skipping, or moving yourself in your own way. There will be a good lunch and plenty of raffle prizes. Your participation helps PMDF in two ways. Your entry fee directly supports our organization, helping with operational expenses as well as contributing to research. In addition, a large number of participants encourages our corporate sponsors to continue to support PMDF and helps us to get additional sponsors.

There are several interesting and informative articles in this issue, so read on, and get registered for MOVE4U!

Sincerely,

A handwritten signature in cursive script that reads "Mark Wadsworth".

Mark Wadsworth
PMDF President

Welcoming our new medical advisor, Dr. Kong Truong

by Tien Nguyen

The Parkinson's and Movement Disorder Foundation would like to welcome the latest addition to our medical advisory board, Dr. Kong Truong.

With his specialty emphasized in Neurology, he completed his residency at Upstate Medical University in Syracuse, NY, completing his fellowship in Clinical Neurophysiology at Loma Linda University emphasizing on electromyography/nerve conduction studies, and EEG. In addition to being a Board Certified Neurologist, he is a member of the American Academy of Neurology and the American Association of Neuromuscular & Electrodiagnostic Medicine. He currently practices at the Parkinson's and Movement Disorder Institute in Fountain Valley, California, managing the clinical studies while also treating patients with neuromuscular disease, Parkinson's disease, headaches, seizures, and other general neurology diseases.



April 2018: World Parkinson's Disease Awareness Month

by Mary Ann Chapman, PhD



April is Parkinson's Disease Awareness Month! Local events are held all over the world to raise awareness and funds for research. Among the most popular events are walks or runs. The PMDF will continue promoting awareness in the month of May with our Move 4U/5K Walk/Run on Saturday, May 19 in Mile Square Park in Fountain Valley, CA. See our website www.pmdf.org and the article in this newsletter for more information. If you can't make it, you can show your support with a donation for research.

Botulinum Toxin for Oromandibular Dystonia

by Mary Ann Chapman, PhD

Oromandibular dystonia is a type of focal dystonia that is characterized by uncontrollable contractions of the lower face, jaw, and tongue. People with oromandibular dystonia often have difficulty chewing, speaking, and opening or closing the mouth. Like other dystonias, oromandibular dystonia is rare and in most cases its cause is unknown. Botulinum toxin injections are the primary treatment for oromandibular dystonia. Medications taken orally are not very effective for oromandibular dystonia and surgical procedures to correct the condition have not been well studied.

Dr. Cynthia Comella, an internationally recognized expert in the treatment of movement disorders, including dystonias, has recently reviewed studies of botulinum toxin treatment for oromandibular dystonia (Toxicon, 2018, doi: 10.1016/j.toxicon.2018.02.006). She reports that most of these studies support the effectiveness of botulinum toxin, although they didn't include control groups and may therefore be subject to bias. The most robust responses are typically seen with jaw closing dystonia. Jaw opening dystonia also responds to botulinum toxin injections although they are more difficult to perform. Tongue dystonia is the most difficult to treat with botulinum toxin because injections must be made into tongue muscles, which can lead to difficulty swallowing.

It is typically challenging to conduct studies for rare conditions such as the dystonias because there are so few patients to participate. Additionally, given that botulinum toxin injections have been used as standard of care for so many years, most people would probably not want to be assigned to a control group in which they received placebo injections. For these reasons, researchers may not

conduct a large, well-controlled study with botulinum toxin for oromandibular dystonia unless a new treatment is developed. In this case, botulinum toxin might serve as the standard of care control group against which the new treatment would be compared.

Current studies in dystonia are attempting to better understand the underlying biology, such as genetics and connections between different brain areas. Researchers are also trying to determine the relationships between dystonias that affect different parts of the body. Such studies may lead to new treatments or help refine existing treatments, or even suggest how several different treatments may complement one another.

Telemedicine in Movement Disorders

by Mary Ann Chapman, PhD

Telemedicine is the use of electronic communication technology to diagnose and treat medical conditions. Telemedicine has the potential to benefit both physicians and patients and is becoming more common for movement disorders, although obstacles still exist.



A recent survey of nearly 600 movement disorder physicians and other healthcare providers from 83 countries asked questions about their experiences with telemedicine (Hassan et al, 2018, *Telemed J E Health*, doi: 10.1089/tmj.2017.0295). Results showed that approximately half of those surveyed used telemedicine for clinical care. The most frequent uses were e-mail (63%), video visits (40%), and video-based education (35%). The most common challenges experienced by healthcare professionals were limitations related to neurological exams and technical difficulties. The biggest benefits they described were reduced travel time and reduced patient costs.

Historically, video technology in medicine was used to treat patients in remote locations, such as rural areas. Although telemedicine is still used for this purpose today, it is increasingly being used to make medical care more convenient for patients by reducing travel time and minimizing physician

visits. Some medical companies now specialize in telemedicine, offering 24-hour access to medical care with on-call physicians.

In movement disorders, the use of wearable sensors is an important technological development that is increasingly being combined with telemedicine. The sensors monitor movement parameters such as tremor that can be transmitted back to physicians for analysis. Such information can be used to help improve medication regimens, including timing, doses, and medication combinations.

For many movement disorders, patients may experience different symptoms—or symptoms that are more or less intense—at home than they do in their physician’s office. In such cases, video visits in which physicians “see” patients in their own homes may be especially relevant. Such visits will probably become more common in the next 5 to 10 years as methods for gaining good clinical information from video improve.

Move4U 5K Walk/Run Fundraiser

Family Friendly Event

**Mile Square Park
Fountain Valley, CA**

Saturday, May 19, 2018

8:30 am: Sign-In

10:00 am: Race Start Time

11:00 am: Lunch Available

First Place Prize - 2 Roundtrip (or 4 One-Way) Southwest E-tickets (valued at \$800!)

Second Place Prize – 4 Knott’s Berry Farm Tickets

Third Place Prize - To Be Announced

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

\$20 Entry Fee Per Person

\$5 – Parking Inside the Park

Free – Street Parking

Lunch, T-shirt, and Beverages are provided for participants

Children ages 12 and under are free to attend

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

Sponsors



**5K Run/Walk
Saturday
May 19, 2018
8:30 a.m.**

Movement Disorders
Move4U 5k
Registration Form

**Mail-in registrations
must be postmarked
by May 15, 2018**

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

EMAIL: _____ PHONE: _____

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

How many child/children you will be bringing under 13: _____ (free)

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 NSTA

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 NSTA, 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

P M D F 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.