



# Dystonia Support Group of Greater Washington DC

February 2016

In Association with the Dystonia Medical Research Foundation



## Message from Sally Presti Support Group Leader of the Dystonia Support Group of Greater Washington DC

Hope you are enjoying this great weather after our winter season. Warm weather and sunshine is so invigorating. We look forward to another full year with our support group. In November we will have our bi-annual conference. It will be a one day conference on November 13, 2016 at Holy Cross Hospital in Silver Springs MD. Come and visit with old friends and learn more about this disease that binds us together. On April 12-13, 2016, I urge you to join us at Advocacy Day where we lobby our US Congress. It is an very interesting and rewarding day. Take care,  
*Sally*

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Message from our Support Group Leader

Calendar of Events

April 3, 2016 Support Group Meeting

Ongoing Clinical Trials at NIH

Advocacy Day

Webinar covering DMRF Accomplishments



**DYSTONIA MOVES THE PARTICIPANTS AT THE GREATER WASHINGTON DC SUPPORT GROUP MEETING**

## Register for Advocacy Day

Advocacy Day will be held April 12-13, 2016 in Washington, DC. Don't miss this empowering and important day of action in Washington, DC. The orientation, legislative briefing, and complimentary dinner will take place on April 12 at the St. Gregory Hotel. On April 13th the dystonia advocates will 'hit the Hill'. You will join with other advocates to meet with Members of Congress and their staff to help them understand what dystonia is and how they can help us. Register today to help make a difference! For more information on participating in legislative advocacy, contact the DMRF at [dystonia@dystonia-foundation.org](mailto:dystonia@dystonia-foundation.org) or 312-755-0198.



## Dystonia Support Group of Greater Washington DC Support Group Meeting April 3, 2016

**Location:** Holy Cross Hospital, 1500 Forest Glen Road, Silver Spring, MD 20910-1484

**When:** April 3, 2016 Social starts at 12:30PM, Speaker starts at 1:00PM

**Speaker: Stephen Grill, M.D.,** Our Support Group's Medical Advisor, Dr. Stephen Grill will discuss a clinical trial for treating cervical dystonia. Dr. Grill and his team at the Parkinson's and Movement Disorders Center of Maryland will conduct a randomized investigator-blinded trial of specific physical therapy to treat cervical dystonia. The trial will be a cross-over design so that patients will be randomized to active therapy for ½ of the duration of the trial either for the first or second three months of the 6 month study. Patients will continue to receive whatever other treatments they are currently receiving. The Knights of Pythias, Pythian Sisters of Maryland, have graciously funded the clinical trial. Dr Gill will be available for questions and answers after his presentation.

**If you like, bring a snack to share. Beverages will be provided.**

**Directions to Holy Cross Hospital 1500 Forest Glen Rd, Silver Spring, MD 20910-1484 301-754-7000**

From I-495, take exit 31, Georgia Ave - Wheaton (Rt. 97 North), Turn right onto Forest Glen Rd, Follow 4 blocks (.3 miles) to Holy Cross Hospital on the right, at the corner of Forest Glen and Dameron Drive

### **Metro Directions to Holy Cross Hospital**

Holy Cross Hospital is located five blocks from the Forest Glen (Red Line) Metro station. From the station, cross Georgia Avenue then walk five blocks down Forest Glen Road. Hospital is on the right.

## CALENDAR OF EVENTS

WHAT	WHERE	WHEN	SPEAKER/TOPIC
Dystonia Support Group of Greater Washington DC Meeting	Holy Cross Hospital 1500 Forest Glen Road Silver Spring, MD 20910-1484	April 3, 2016	Dr. Grill on cervical dystonia clinical trial, followed with a Q&A on dystonia.
Dystonia Support Group of Greater Washington DC Meeting Everyone invited.	Holy Cross Hospital	May 22, 2016	Dr. Appel from the National Rehab Hospital on Living with Chronic Pain
Dystonia Support Group of Greater Washington DC Meeting	Holy Cross Hospital	Sept 18, 2016	We need your suggestions on topics. Please call Sally Presti at 301-627-1657
Advocacy Day in Washington DC	St. Gregory Hotel on April 12 Capitol Hill on April 13	April 12-13, 2016	Advocates will meet with their legislators.
DMRF Family Symposium	Holiday Inn Chicago Mart Plaza River North 350 West Mart Center Drive Chicago, IL 60654	Aug 12-14, 2016	Sessions for children (age 6+) & teens with dystonia, adults/ parents with dystonia, children and loved ones of dystonia patients, and spouses/ caregivers.
Greater Washington DC Dystonia Conference	Holy Cross Hospital	November 13, 2016 Conference	Numerous speakers

## NIH CLINIC DYSTONIA STUDIES

### Topic Presented by Dr. Karin Mente at our November 15 , 2015 Support Group Meeting

**Karin Mente**, a clinical fellow in the Human Motor Control Section of the National Institute of Health, National Institute of Neurological Disorders and Stroke (NIH/NINDS), discussed the Human Motor Control research studies and research in the dystonia community worldwide.

#### **Trial: Natural History and Biospecimen Repository for Dystonia**

**Description:** This collaborative, international effort has two primary goals. The first is to create a biospecimen repository and associated clinical database to be used as a resource for dystonia and related disease research. The second goal is to create and validate various rating scales for focal dystonias to be used during a typical clinical examination. Across sites, the investigators hope to enroll at least 5,000 adult patients.

**Eligibility:** Diagnosed with primary dystonia

**Design:** Subjects of this study will be asked to complete a neurological exam which will be videotaped, complete some questionnaires, and donate a blood sample. A study visit will take between 45 minutes and 1 hour depending upon which portions of the study a subject completes. A subset of subjects will be asked to return no more often than once a year for a one hour follow-up visit.

**Contact:** Ami R Rosen, MS, CGC; (404) 727-3381; arosen3@emory.edu

#### **Trial: Transcranial Magnetic Stimulation for Focal Hand Dystonia**

##### **Description: Background:**

The brain has natural electrical rhythms of brain activities. These rhythms may be different in people with movement disorders, such as dystonia (involuntary muscle movement, cramps, or tremors). Focal hand dystonia, also known as "writer's cramp" or "musician's cramp," is a painful condition that affects the hand and arm muscles. Researchers want to use transcranial magnetic stimulation (TMS) to study brain rhythms in people with and without focal hand dystonia.

**Eligibility:** Individuals between 18 and 70 years of age who are right-handed and have focal hand dystonia.

**Design:** Participants will be screened with a physical exam and medical history. This study includes two tests: a pilot test and a main test. The pilot test will determine the frequency of TMS that will be used in the main test. Participants may be in one or both tests. Each test requires a single outpatient visit that will last up to 5 hours.

Participants will have a base test to see how their muscles respond to TMS. This will look at the electrical activity of the muscles. Participants will have a wire coil held on their scalp. A brief electrical current will pass through the coil. It creates a magnetic pulse that stimulates the brain. Researchers will test the TMS on the right and left sides of the head. This will help find the spot that activates the finger muscles, and see how much TMS is needed.

In the main test, participants will have repetitive TMS (rTMS). rTMS involves repeated magnetic pulses delivered in short bursts. There will be four pulses in each burst. Participants will have multiple bursts during the test. This test will look at how the muscles of the hand and fingers respond to brain stimulation. Treatment for focal hand dystonia will not be provided as part of this study.

**Contact:** Elaine Considine, R.N. (301) 435-8518; considinee@ninds.nih.gov

**More information about on-going and completed clinical trials is available at**

<https://clinicaltrials.gov/search/?term=Dystonias>

## NBC 4 HEALTH and FITNESS EXPO

On January 10 & 11, 2016, over 85,000 attended the annual NBC4 Health and Fitness Expo at the Washington Convention Center. Thank you to our dedicated volunteers at our booth for increasing dystonia awareness: Frank Presti, Patricia Price, Irene Rudyj, Shidfar Shahriary, Kathy Shartzter, Mike Tabisz, Hunter Webster, and Dea Zugby. The volunteers felt good about reaching out and educating people about dystonia. It is a great feeling if you help someone.

### DMRF HAS ITS OWN YOUTUBE CHANNEL

Check it out at <http://www.youtube.com/facesofdystonia>

### DMRF HAS ITS OWN TWITTER ACCOUNT

Check it out at <https://twitter.com/dmrf> Over 3,000 people follow their tweets.

### ARTICLES AND REVIEWS ON DYSTONIA FROM THE MEDICAL LITERATURE

DMRF provides a list of recent articles concerning dystonia from the medical literature. Check them out at <https://www.dystonia-foundation.org/research/for-researchers/recent-publications>. They may difficult for us lay people to follow but it provides hope that research is happening all over the world.

### HAVE YOU REGISTERED?

The goal of the Global Dystonia Registry is to support future dystonia studies, including clinical and research trials. Although the focal dystonias have many different manifestations, most experts believe they share a common pathogenesis or mechanism that causes the disorder. The common causes may be a similar gene defect, similar lifetime experiences, or both. Collecting information from different patient populations may help us identify the common features that they may share.

Patients can register at: <http://www.globaldystoniaregistry.org/>

### RENEW YOUR SUPPORT GROUP MEMBERSHIP

Consider renewing your Dystonia Support Group of Greater Washington DC membership by completing the form on the last page of this newsletter. Any contributions you make pays for the postage and printing of this newsletter.

**BRAIN DONORS ESSENTIAL FOR IMPORTANT RESEARCH:** Consider brain donation. For more information or to begin the registration process, visit <https://www.dystonia-foundation.org/get-involved/participate-in-research/become-a-brain-donor> or contact the DMRF at 800-377-3978.

**STAY IN TOUCH:** Sign up for the DMRF monthly e-newsletter for the latest updates and announcements at <https://www.dystonia-foundation.org/get-involved/stay-connected> or contact the DMRF at 800-377-3978.

## WEBINAR PRESENTED TO DMRF SUPPORT GROUP LEADERS

Janet Heishetter, DMRF's Executive Director, conducted a webinar for the DMRF Support Group Leaders on January 27, 2016. DMRF is celebrating its 40th anniversary but would not mind going out of business if a cure for dystonia was found. The webinar covered the following topics.

### REVIEW OF 2015 ACCOMPLISHMENTS

- The DMRF is directing research via contracts to fund the creation of important cell and animal models, pursue potential new drug targets, collect data on specific proteins, and better understand specific neurons and pathways in the brain associated with dystonia. The Medical and Scientific Advisory Council (MSAC) is comprised of pre-eminent researchers and clinicians from various scientific disciplines. The members are responsible not only for grant review but also for setting the direction of the research to find more effective treatments and ultimately a cure.
- The DMRF is fostering the next generation of dystonia leaders by offering one-year fellowships to support clinical training of neurologists in preparation for a clinical and/or research career in movement disorders with special focus on dystonia. The Clinical Fellowship Program is made possible by a grant from Merz Pharmaceuticals. Five fellows will start in July.
- We are pleased at Janet Heishetter's appointment to the council at NIH/NINDS.
- DMRF is establishing The Mahlon DeLong Young Investigator Award. The Award will recognize and support an early career PhD or MD researcher pursuing ambitious and creative research in dystonia.
- DMRF has many educational and support activities such as the *Dystonia Dialogue* magazine, a newly developed website at <https://www.dystonia-foundation.org/>, Advocacy Day, Dystonia Zoo Walks and support groups. The Advocacy Day effort helped obtain over 5 million dollars of research funds from the Dept of Defense and obtain a 2 billion increase to the NIH budget.
- In an effort to help with dystonia research, DMRF urges us to register in the Global Dystonia Registry at <http://www.globaldystoniaregistry.org/>. The goal of the Global Dystonia Registry is to support future dystonia studies, including clinical and research trials, through the collection of data on persons affected by dystonia.
- By DMRF providing the administration support to the Dystonia Coalition, an additional million dollars went to research.

### PLANS FOR 2016

- DMRF will have a team of runners in the New York City Marathon in November. Each team member has committed to raising \$2,500.
- Awareness—Dystonia Moves Me Campaign. Tell your story to neighbors. Change profile picture on social media to dystonia related image. Tell your dystonia story in a YouTube video. Pitch your story to the local news. DMRF will help with a template. Jessica Feeley is the point of contact for this. Her contact information is [jfeeley@dystonia-foundation.org](mailto:jfeeley@dystonia-foundation.org) (912) 510-0337.
- Advocacy Day will be held April 12 & 13, 2016 in Washington DC.
- DMRF Family Symposium will be held August 12-14, 2016 in Chicago.
- 2016 Dystonia Zoo Walks will happen in over a dozen different cities.
- 2016 Virtual Walk Fund Raiser will happen in September.
- An anonymous donor wants to help increase participation and increase donations via Dystonia Zoo Walks by matching funds.



## Dystonia Support Group of Greater Washington DC New Member/Update Form

Please complete this form if you are a new member, renewing your membership or if any of your information has changed.

Name: \_\_\_\_\_ Date: \_\_\_\_\_  
 Address: \_\_\_\_\_ Apt. \_\_\_\_  
 City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_  
 Phone # (Home) \_\_\_\_\_ Phone # (Cell) \_\_\_\_\_ Phone # (Work) \_\_\_\_\_

E-mail Address: \_\_\_\_\_

Do you wish to receive the newsletters by email?: Yes \_\_\_ No \_\_\_

Type of Dystonia: \_\_\_\_\_

Doctors who are treating you: \_\_\_\_\_

Donation: \_\_\_\_\_ Please make checks payable to: Greater DC/DMRF Support Group

Notes:

\_\_\_\_\_

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Please mail this form to: **GW Dystonia Support Group**  
**c/o Hunter Webster**  
**1206 Night Star Court**  
**Reston, VA 20194**



### Dystonia Support Group Contact Information

- **Sally Presti**  
Leader/Telephone Support  
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- **Shidfar Shahriary**  
Assistant Leader  
301-948-5261
- **Hunter Webster**  
Treasurer  
703-689-2802  
hunter.webster@ihrco.com
- **Virginia Foster**  
Secretary/Membership/Newsletter  
301-904-3434  
Dcdystonia.editor@yahoo.com

### Web Watch

- Our support group website is at <http://www.dystoniadc.com/>
- Dystonia related social forums are listed under the Web Watch page of our website at <http://www.dystoniadc.com/>
- The Dystonia Medical Research Foundation's website is <https://www.dystonia-foundation.org/>
- To search for clinical trials go to <http://www.clinicaltrials.gov/> and [www.centerwatch.com](http://www.centerwatch.com)

### Other Dystonia Support Groups

- **DC Metro Spasmodic Dysphonia Support Group**—contact Lois Jackson at loismjackson@hotmail.com
- **Benign Essential Blepharospasm Research Foundation (BEBRF)**—contact Barbara Benton at dir-e@blepharospasm.org or call 410-884-9048
- **National Spasmodic Torticollis Association** —Contact Margaret Teed at teed-fam@verizon.net or call 703-533-8698