



# Dystonia Support Group of Greater Washington DC

February 2015

In Association with the Dystonia Medical Research Foundation



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

### Core Group Changes

2015 brings changes to our core group's leadership board. After many years of giving their time and talent Roberta Senzel and her daughter Marcie Povitski (membership and news letter) will be leaving and volunteering with the DMRF national office which sponsors our support group. I want to thank Roberta and Marcie for their years of dedicated service to us. Virginia Foster, who is our group's secretary, will be taking over their responsibilities.

### Core Group Meetings

The core group leadership board meets once between each of our Support Group meetings. We share ideas, plan meetings, events, etc. The core group welcomes new volunteers at any time. This is "our group." Come and share your ideas and talents with us. Contact Sally (301) 627-1657 or e-mail Virginia at [river\\_house\\_farm@yahoo.com](mailto:river_house_farm@yahoo.com).

### Support Group Meetings

Although we may have different kinds of dystonia, we are dealing with many of the same issues and frustrations of living daily with dystonia. Come to our Support Group Meetings held at Holy Cross Hospital for an exchange of ideas where old and new friends meet.

Social time begins at 12:30 PM. Our featured speaker begins at 1:00 PM. There is time after our speakers to meet with other members and informally talk with Dr. Stephan Grill, our support group's medical advisor and a movement disorder neurologist. Dr. Grill always speaks on a "timely issue" followed by an active Question and Answer session.

### Need a ride to Support Group Meetings?

If you are in need of a ride to our Support Group Meetings or you can provide a ride for someone, please contact our Ride Share Coordinators: **Dea Zugby at [deazugby@aol.com](mailto:deazugby@aol.com) or me at 301-627-1657.**

### Mark Your Calendars

Mark your 2015 calendars for Sunday afternoons at Holy Cross Hospital. All are welcome to our support group meetings. Dates for 2015: March 15, May 31, September 27 and November 15. Social time begins at 12:30PM.

Take care,

*Sally*

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## Dystonia Support Group of Greater Washington DC Support Group Meeting March 15, 2015

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

**When:** March 15, 2015 Social Hour starts at 12:30PM, Speaker starts at 1:00PM

### **Topic: INTRODUCTION TO ADAPTED TOOLS OF YOGA**

Research shows that the practices of yoga can decrease stress, regulate emotions, and promote resiliency. As part of an integrative approach to symptom management, yoga may provide a means for self care and a vehicle for self awareness. This session will provide an introduction to the appropriately adapted tools of yoga - postures, breath awareness and meditation - to encourage the relaxation response, cultivate mindfulness and promote self efficacy.

**Speaker: Lynne Valdes** has an extensive background in adaptive yoga and a wide range of experience working with individuals with chronic conditions and disabilities. She is completing a Master of Science degree in Yoga Therapy at Maryland University of Integrative Health, the first program of its kind, and pursuing a graduate certificate in Neuropsychology from Ball State University. Lynne is certified through the American Viniyoga Institute as a 500 hour Viniyoga teacher and through Warriors At Ease as a yoga and meditation teacher for military populations. She is also registered with Yoga Alliance as an E-RYT 500, and is a member of the International Association of Yoga Therapists.

**Directions to Holy Cross Hospital 1500 Forest Glen Rd, Silver Spring, MD 20910 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

*Go into main entrance of hospital, register & obtain a visitor's badge at the front desk; ask for directions to the Dystonia Meeting in the Education Center.*

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

Holy Cross Hospital is located five blocks from the Forest Glen (Red Line) Metro station. From the station, take the Montgomery County Ride On Bus 8 toward the Silver Spring station. The bus stops at the main hospital entrance.



### **Dystonia Support Group of Greater Washington DC Contact Information**

- **Sally Presti**  
Leader/Telephone Support  
301-627-1657  
sfpresti@verizon.net
- **Shidfar Shahriary**  
Assistant Leader  
301-948-5261
- **Hunter Webster**  
Treasurer  
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hunter.webster@ihrc.com
- **Virginia Foster**  
Secretary/Membership/Newsletter  
301-904-3434  
river\_house\_farm@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

## CALENDAR OF EVENTS

WHAT	WHERE	WHEN	CONTACT
Meetings of the Dystonia Support Group of Greater Washington DC	Holy Cross Hospital 1500 Forest Glen Road Silver Spring, MD 20910	12:30PM to 3:30 PM on <ul style="list-style-type: none"> <li>• March 15, 2015</li> <li>• May 31, 2015</li> <li>• September 27, 2015</li> <li>• November 15, 2015</li> </ul>	Sally Presti Leader 301-627-1657 sfpresti@verizon.net
2015 Dystonia Advocacy Day	Capitol Hill Washington DC	April 14 and 15, 2015	Register online at: <a href="http://goo.gl/vPbcDx">http://goo.gl/vPbcDx</a> or call 312.755.0198.
Blepharospasm Maryland Support Group Meeting Guest Speaker— Stephen Reich, MD Professor of Neurology University of Md	Baltimore Jewish Community Center 5700 Park Heights Ave Baltimore, MD 21215	May 3, 2015, Sunday 1 pm	Norm Dubin 6210 Biltmore Ave. Baltimore, MD 21215 410-358- 5014 normdubin@gmail.com

### November 2014 Dystonia Conference was a Great Success!!!!

#### Thanks to the efforts of the following:

- All the participants who attended the conference. We hope you found it informative.
- Dr, Stephen Grill MD Ph.D., the support group's medical advisor, for his help in acquiring speakers, sponsors and program support,
- Dystonia Medical Research Foundation (DMRF) for sponsorship, materials and event assistance,
- Janet Hieshetter, Executive Director of DMRF, for her assistance in planning the event,
- Paula Schneider national support groups chairperson for event assistance,
- Holy Cross Hospital for hosting the event free of charge to our group, for assistance in setting up the conference rooms and for the free parking,
- Barbara Benton, eastern coordinator Benign Essential Blepharospasm Research Foundation for chairing the event,
- Medtronic, MERZ, and Allergan for financial assistance which provided the free attendance,
- Roberta Senzel and family for coordinating the lunch and refreshments,
- Virginia Foster who worked with Dr. Grill and the DMRF for six months to plan the event.

#### Shop Online and Donate to DMRF

- Through the Amazon Smile Program, Amazon donates 0.5% of the price of eligible purchases. Start each shopping session at the URL <http://smile.amazon.com> and designate DMRF as your charity of choice.
- Through the Ebay's Giving Works program you can sell items online and give a portion to DMRF. Follow this link to see items friends of the DMRF are currently selling: <http://givingworks.ebay.com/charity-auctions/charity/dystonia-medical-research-foundation/1390/>



## DYSTONIA MEDICAL RESEARCH FOUNDATION 2015 DYSTONIA ADVOCACY DAY

**Location:** Capitol Hill, Washington, DC

**From:** April 14, 2015 at 12:00pm **to:** Wednesday, April 15, 2015 at 5:00pm

April 14, 2015 Agenda: Legislative training/preparing volunteers for meetings in Congressional offices.

April 15, 2015 Agenda: Volunteers meet with Members of Congress and/or Congressional Staff

It is more important now than ever that Members of Congress are educated as to what dystonia is and how they can help. The DMRF serves as the organization responsible for coordinating the annual advocacy activities of the five groups partnered in the Dystonia Advocacy Network (DAN), including Advocacy Day, scheduled for April 14 and 15, 2015 in Washington, DC.

The 2015 Legislative agenda will be focused on expanding dystonia research opportunities including support for the Dystonia Coalition through the National Institutes of Health (NIH) and also pursuing funding through the Department of Defense, where past legislative successes have provided millions of dollars in critical funds that were previously unavailable to dystonia researchers. Access to care is also a priority issue for the DAN and it is important for legislators at the federal as well as state levels to hear from patients how inadequate reimbursement is limiting or preventing treatment for dystonia.

The DMRF is proud to work with the Benign Essential Blepharospasm Research Foundation (BEBRF), DySTonia, Inc., National Spasmodic Dysphonia Association (NSDA) and National Spasmodic Torticollis Association (NSTA) on these important activities. Annually dystonia organizations come together as "DAN" (Dystonia Advocacy Network) to educate our congressmen and senators on legislative issues of importance to the dystonia community. Volunteers come from across the U.S. for this very important day. Advance registration is required for participation. Volunteers are assigned to constituency groups and appointments are scheduled on Capitol Hill. For interested volunteers, issues are reviewed on Tuesday afternoon April 14, followed by a dinner hosted by DMRF for all DAN Advocacy Day participants.

To register for Dystonia Advocacy Day, visit: <http://goo.gl/vPbcDx>

**Questions? Contact the DMRF at 800-377-3978 or [dystonia@dystonia-foundation.org](mailto:dystonia@dystonia-foundation.org)**

### Can dystonia go into remission and reappear?

(Reprinted from the DMRF website under Frequently Asked Questions)

Yes, but remission happens only rarely. It was once believed that 10% of people with dystonia might have such a spontaneous remission. It is probably much less than that. More frequently, instead of a true remission, the severity of dystonic postures may be reduced for months or years in a small minority of patients. Nearly everyone has some degree of day-to-day fluctuation in the severity of his or her symptoms. For a few, the fluctuation may be so much better and for such a long time that it seems like a remission. However, a careful exam will still reveal some involuntary postures. Those who do seem to have a true remission are likely to again have symptomatic dystonia sometime later.



## DMRF and Cure Dystonia Now Announce Collaboration to Investigate Possible New Treatment

® Medication May Lessen Dystonia with Fewer Side Effects than Existing Drugs

The Dystonia Medical Research Foundation (DMRF) and Cure Dystonia Now (CDN) are collaborating to co-support a research investigation that may lead to a new drug for dystonia, the third most common movement disorder following essential tremor and Parkinson's disease. The medications most frequently prescribed to treat this debilitating disease are ironically those with some of the highest incidence of intolerable side effects, which limit their use. A team of American and European investigators is exploring whether a drug called AZD1446 could potentially provide relief for dystonia patients without the unintended effects frequently caused by existing pharmacological therapies.

The investigation is led by David Standaert, MD, PhD, Professor and Neurology Chair at University of Alabama and includes Antonio Pisani, MD, PhD, Associate Professor of Neurology at University of Rome Tor Vergata.

Art Kessler, President of the DMRF, explains: "This project addresses two important issues for the dystonia community: We need additional treatment options and we need to find new ways to offer treatment with minimal side effects. This project provides an important opportunity to investigate a possible new medication for dystonia while pursuing a better quality of life for patients." Kessler developed an especially debilitating childhood onset form of dystonia at age eight and knows firsthand the challenges inherent in treating the disease.

Marc Miller, Director and Co-President of CDN states, "Our priority is to work with the brightest and most motivated doctors and scientists, and our goal is to discover new treatments. This project is an exciting opportunity to do both." Two generations of the Miller family are affected by dystonia.

Dystonia is a neurological disorder that causes skeletal muscles to contract or spasm involuntarily, resulting in twisting, repetitive movements and/or sustained, abnormal postures. A person who is affected by dystonia struggles against the movements of his/her own body to walk, sit or rest comfortably, eat, write, and/or speak. It may be impossible to sit still. Treatment typically requires a combination of approaches including oral medications, botulinum neurotoxin injections, surgical interventions, and supportive therapies such as physical therapy. In some people, a class of drugs called anticholinergics may replace or compound the physical symptoms with equally disabling cognitive effects such as drowsiness, hallucinations, and memory difficulties. Striking a balance between controlling the dystonia and preserving the ability to function in daily life is a challenge for physicians and patients alike.

Dystonia results from improper signals in the nervous system that instruct muscles to contract excessively. Experts do not yet fully understand the neurological mechanism that causes the abnormal muscle contractions, but the origins appear to stem from an imbalance of neurotransmitters in the brain and changes in brain cell synapses. Standaert and team are using a genetically engineered mouse with abnormal neuronal signaling to examine whether AZD1446 can correct the abnormal signaling and restore the balance of neurotransmitters. In separate studies, the drug has been examined for use in treating attention deficit/hyperactivity disorder and Alzheimer's disease.

### Would you like to save your Support Group some money?

You can save your Support Group the cost of printing and mailing the newsletter if you choose to receive your newsletter via e-mail not United States Post Office. If you would like to receive your newsletter via email, just send your name and email address to [dcdystonia.editor@yahoo.com](mailto:dcdystonia.editor@yahoo.com). Thank you.



## 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**