



Dystonia Support Group of Greater Washington DC

MAY 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

Dear Friends,

Springtime is here! Everything is blooming. We want **you** to bloom, too!! To help towards that goal, we have two terrific speakers for our May 22 meeting. Dr. Philip Appel, Ph.D., Director of Psychological and Neuropsychological Services with Medstar Rehabilitation Network will speak on "How to Live Well and Suffer Less in Spite of Persistent Pain." Remember our meetings are not limited to just those affected by dystonia. Please invite anyone dealing with pain. All are welcome. The second half of our meeting will feature a presentation by Dr. Stephen Grill, M.D., Ph.D., Parkinson and Movement Disorders Center of Maryland, (medical advisor to our Dystonia Medical Research Foundation sponsored support group). This will be followed by an always enthusiastic and informative open discussion of questions, issues, sharing by attendees, led by Dr. Grill. The meetings are always very information. Come. Bring a friend and we look forward to seeing you!

Happy Spring!!!

Always,

Sally

PS—Save these dates: September 18, 2016 Support Group Meeting

November 13, 2016 Free all day dystonia community symposium

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Message from our Support Group Leader

Calendar of Events

May 22, 2016 Support Group Meeting—Living Well with Pain

Advocacy Day

Dystonia Community Symposium November 13, 2016 Holy Cross Hospital

Come to our support group's fall symposium. Many speakers are planned covering a wide variety of topics. Admission is free. Lunch will be provided. Please email Virginia Foster at dcdystonia.editor@yahoo.com or call Sally at (301) 627-1657 with your topic suggestions. We want this all day, free program to address your "issues" with dystonia. Just let us know what you want this day to be for you.



Dystonia Support Group of Greater Washington DC Support Group Meeting May 22, 2016

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

When: May 22, 2016 Social starts at 12:30PM, Speaker starts at 1:00PM

Speaker: Philip Appel, PhD, director of Psychological and Neuropsychological Services, has been with the MedStar National Rehabilitation Network since 1987, working with individuals who experience persistent pain that interferes with their performance and obtaining quality of life. Dr. Appel works to help individuals adjust to the life challenges that are brought on by disability and chronic illness or injury. He teaches a variety of mental practice techniques to enhance performance through learning mentally the movement patterns needed to execute a complex motor pattern. Self-hypnosis, guided imagery, relaxation, and meditative techniques are all used to provide the individual with a greater awareness of self and ability to regulate performance and influence desired outcome.

Dr. Appel has written extensively about the use of hypnosis in enhancing performance in rehabilitation. He is a fellow of the American Society of Clinical Hypnosis, a past president of that organization, is listed in the National Register for Health Service Providers in Psychology, he has a Certificate of Professional Qualification in Psychology from the Association of State and Provincial Psychology Boards, and is licensed in both Maryland and the District of Columbia. Dr. Appel specializes in pain management, adjustment to illness, injury and disability, behavioral medicine, consultations, performance enhancement, and executive health coaching.

Dr. Appel, in his talk, will discuss some of the concepts related to learning how to live well and suffer less in spite of having persistent pain. He will share what his patients have taught him over the last 30 years.

CALENDAR OF EVENTS

WHAT	WHERE	WHEN	SPEAKER/TOPIC
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
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.
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
Dystonia Community Symposium	Holy Cross Hospital	November 13, 2016 Conference	Numerous speakers

DYSTONIA ADVOCACY DAY

The Dystonia Advocacy Network (DAN), which brings dystonia groups together, had an important and empowering annual event on Capitol Hill in Washington DC on April 13, 2016. It was an exciting opportunity to express our support and/or concerns on issues and bills before the U.S. Senate and the House. The following describes our “asks” that we presented to our representatives.

Advance Research

1. Provide the National Institute of Health (NIH) with at least \$34.5 billion in Fiscal Year 2017. Investment in NIH research has led to improvements in our scientific understanding of dystonia.
2. Continue to recognize dystonia as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for Fiscal Year 2017. This program has funded over \$5,700,000 research projects.

Improve Patient Care

1. Cosponsor the Patient’s Access to Treatments Act (H.R. 1600) which would stop health insurance companies from moving more expensive so called specialty drugs onto specialty tiers that require the patient to pay higher out of pocket expenses.
2. Cosponsor the Access to Marketplace Insurance Act (H.R. 3742) which would prevent a return to pre-existing condition discrimination.

At the end of the day we were exhausted invigorated with success, and had new friends. Wonderful!! Thank you to all volunteers. It was great!!





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:

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

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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

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