



Dystonia Support Group of Greater Washington DC

MARCH 2018

In Association with the Dystonia Medical Research Foundation

NBC HEALTH & FITNESS EXPO

We will be at booth number 4094 at the upcoming NBC Health Expo on March 10-11, 2018 at the Washington Convention Center. If you are able to help tend the booth, please contact Sally Presti., 301-627-1657 sfpresti@verizon.net.

DYSTONIA ADVOCACY DAY

March 19, 2018 to: Tuesday, March 20, 2018 (all day event)

You can help educate Congress on dystonia and the needs of the dystonia community. Your voice matters, your story matters. Register today! (<https://www.dystonia-foundation.org/site/event/37302>)

Join Dystonia Advocacy Network volunteers from across the country for legislative training and meetings in Congressional offices to advocate on behalf of the dystonia community.

Day 1: Legislative training and preparing volunteers for meetings in Congressional offices.

Day 2: Volunteers spend the day on Capitol Hill in meetings with Members of Congress and/or Congressional Staff

Location: Day 1 & 2 Washington Plaza Hotel, 10 Thomas Circle NW, Washington, DC 20005

Day 2 Capitol Hill

DMRF HONORS SALLY PRESTI

Dr. Stephen Grill presented Sally Presti with an DMRF service award in recognition of her 23 years of dedicated service. Sally is our Support Group Leader and the heart and sole of our group. As Dr. Grill explained, Sally works unselfishly for the group; securing speakers to raise awareness, reaching out to newly diagnosed individuals, and advocating for a higher level of care for individuals with dystonia.





Dystonia Support Group of Greater Washington DC Support Group Meeting March 18, 2018

Dystonia Support Group of Greater Washington DC

Support Group Meeting

Location: Holy Cross Hospital, 1500 Forest Glen Road, Silver Spring, MD 20910-1484 (301) 754-7000

When: March 18, 2018 Informal social starts at 12:30PM, Program starts at 1:00PM

Speakers:

1:00—1:15 Announcements—Sally Presti

1:15—2:15 **Dr. Codrin Lungu**—Overview of Dystonia Research Efforts and Potential Upcoming Therapies

2:15—2:30 Question and Answer Period

Speaker: Dr. Codrin Lungu is a Program Director in the Division of Clinical Research Program Director at the National Institute of Health, National Institute of Neurological Disorders and Stroke

He has a background and expertise in Movement Disorders, with particular interests in Parkinson disease, dystonia, deep brain stimulation therapy and neurotoxins. Most recently, Dr. Lungu has been the Chief of the NIH Parkinson clinic, which he has led for over 5 years. He has also established, in collaboration with the Surgical Neurology Branch, the first NIH Deep Brain Stimulation program, and has led the NIH Botulinum Toxin clinic for 8 years. His experience includes research in imaging biomarkers, neuromodulation, and early clinical trials of novel therapeutic agents. He has been co-directing the NIH Movement Disorders fellowship and remains involved in education and promotion of research.

Dr. Lungu earned his MD in Romania; performed neuroscience research at the University of Rochester; completed his Neurology Residency in the North Shore –LIJ campus of Albert Einstein College of Medicine; and completed fellowships in Movement Disorders at Harvard Medical School (Beth Israel Deaconess Medical Center) and NIH (Human Motor Control Section).

His current interests include research and trials in movement disorders, including Parkinson's disease, dystonia, tremor, myoclonus; clinical applications of neuromodulation, particularly deep brain stimulation; clinical applications of therapeutic neurotoxins; studies of novel therapies in neurodegenerative disorders, movement disorders and other neurologic conditions.

Upcoming Dystonia Support Group Meetings	Holy Cross Hospital 12:30pm 1500 Forest Glen DR, Silver Spring, MD
May 6, 2018	Mid-Atlantic Brain & Neurological Rehab Center, http://mabnr.com/ Neuroplasticity Concept
September 23, 2018	Topic/Speaker to be determined. Contact Sally Presti with ideas. 301-627-1657 sfpresti@verizon.net
November 4, 2018	One Day Conference—Theme is Teamwork

We Celebrated our 30th Anniversary at our Support Group Meeting November 19, 2017

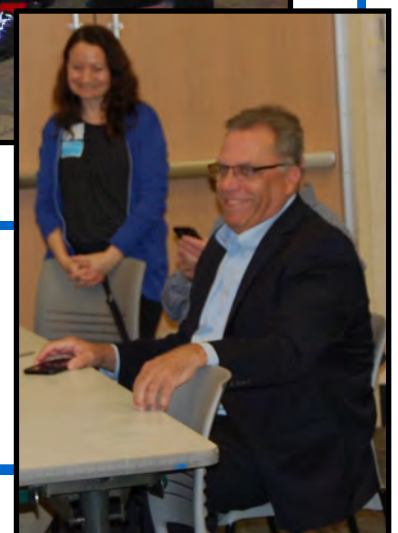
Old and new members shared in our celebration. Sally Presti, our group leader, provided a history of the group and thanked all the volunteers that have kept the group vibrant for the last 30 years. Dr. Stephan Grill recapped the medical advances made and the spoke to the new ways researchers are looking at genetics in an attempt to develop new treatments.

Dick Stuart, MC, DMin provided an inspiration talk centering around his struggle with spasmodic dysphonia (SD) and writer's cramp. As with many dystonia patients, it took years for him to be diagnosed. He received botulinum toxin injections for the SD, then in 2012, he underwent selective laryngeal adductor denervation-reinnervation surgery (SLAD-R). This procedure was introduced by Dr. Gerald Berke of UCLA in the late 1990's. The concept is to sever the anterior branch of the recurrent laryngeal nerve. This denervates the spasming laryngeal adductors. To return strength to the voice, a branch of the ansa cervicalis nerve that normally supplies some relatively "unimportant" neck muscles is anastomosed (connected) to the severed nerve. It takes 3 months to a year for tone to begin to return to the adductory muscles. Mr. Stuart has had very good success from the surgery.



THANKS TO MEDTRONIC

Medtronic graciously provided lunch for our group. It was delicious.



TIME TO RENEW

Spring is around the corner and its time to renew your membership with the Dystonia Support Group of Greater Washington DC. Your dues are used to pay for publishing and posting our newsletter as well as supporting the DMRF. Dues paid are appreciated but not required.



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: **Greater Washington Dystonia Support Group**
c/o Hunter Webster
1206 Night Star Court
Reston, VA 20194