



# Dystonia Support Group of Greater Washington DC

FEBRUARY 2019

In Association with the Dystonia Medical Research Foundation

## NOTE FROM OUR SUPPORT GROUP LEADER

Dear Friends,

After a busy holiday season, we are looking forward to another year of providing our dystonia community with information from our network of caring professionals. As we start the year, let us reach out with understanding and hope. No matter what type of dystonia, we can come together at our support group meetings to share our journeys in search of treatments and strategies in order to live our best.

In an effort to encourage sharing of information, our meetings this year will start at 1:00 with a half an hour for our members to share their successes and discoveries. Announcements will be made at 1:30 followed by our featured speaker(s).

Our March 3, 2019 meeting will feature Dr. Zachery Levine, MD, neurosurgeon and our medical advisor Dr. Stephen Grill, MD, PhD. (See following page for their biographies.) They will discuss the Deep Brain Stimulation (DBS) surgery, the new devices available and the new technologies which offer hope for those not responding to medication and Botulinum toxin injections. Dr. Grill will speak on what to expect after DBS surgery.

Our May 19 meeting will feature Andrea Schultheis, MS, OTR/L, a registered and licensed occupational therapist. She will speak on the everyday strategies you can use to live "well" with dystonia. She will discuss body positioning directed at easing the dyskinesia of cervical dystonia, writing tools to help with writer's cramp, eating strategies to help with oralmandibular dystonia and other practical life support skills.

Immediately following our March and May meetings, our core group of volunteers will meet to discuss our all day symposium to be held September 15, 2019 at Holy Cross Hospital. Please plan to stay and join us to share your ideas on topics, speakers, and how to make the symposium better.

Our last meeting of 2019 will be held on November 17. Topics and speakers are undecided at this time. Please let us know if there is a specific topic you would want addressed.

Now I must say goodbye. It has been such a great honor to have been a part of your dystonia community. I have learned a great deal from you. Our family has decided that Frank and I should move closer to them so we will be leaving the Washington DC area. March 3 will be our last meeting. We will try to attend the September symposium. Please come to the March 3 meeting so I may say good bye to my many friends.

Always Sally

(301) 627-1657 preferred

[sfpresti@verizon.net](mailto:sfpresti@verizon.net)



## March 3, 2019 Support Group Meeting

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

**When:** March 3rd, 2019 Informal social starts at 1:00 PM, Program starts at 1:30PM **Please note the change in start time.**

1:00—1:30 Sharing our dystonia journeys

1:30—1:45 Announcements—Sally Presti

1:45—2:30 **Dr. Zachery Levine and Dr. Stephen Grill** will discuss Deep Brain Stimulation (DBS) surgery, the new devices available, the new technologies which offer hope for those not responding to medication and Botulinum toxin injections and what to expect after DBS surgery.

2:30—2:45 Dr. Stephen Grill—Question and Answer Period

2:45—3:00 A Farewell Tribute to Sally Presti

3:00—3:30 Core group planning session. All are invited.

**Speakers:** **Dr Zachery Levine** is a board-certified neurosurgeon and Fellow of the American Academy of Neurological Surgery. He has advanced training in cranial base surgery and stereotactic/functional surgery for movement disorders and epilepsy. In addition, he has extensive experience in Deep Brain Stimulation (DBS), image-guided, computer-assisted microsurgery, minimally invasive spinal surgery and artificial disc replacement. He is the Director of Neurosurgery and Neurosciences at Holy Cross Hospital. In the constantly innovating field of neurosurgery, Dr. Levine keeps up. He was the first to perform minimally invasive brain surgery using the BrainPath system in the metropolitan D.C. region. And has been a leader in the neuromodulation/DBS community worldwide. Dr. Levine proctors other surgeons performing DBS, locally and internationally. He is a key opinion leader on the topic and served on the technical advisory board of the company that makes the only DBS devices approved for use by the FDA.

A graduate of Dartmouth College, Dr. Levine completed medical school at New York University School of Medicine in the honors program. He did his residency in neurological surgery at the George Washington University Hospital. Dr. Levine has taught cranial base surgical approaches at national meetings. He collaborates with the National Institutes of Health, Medical Neurology Branch. His clinical research in skull base surgery, cerebrovascular surgery, and functional neurosurgery has been published in peer-reviewed journals and textbooks. He patented a technique for cellular transplantation in neurodegenerative diseases and movement disorders.

He is also an alumnus member of the Osler Society. His efforts in neurosurgery have been recognized by induction into the Alpha Omega Alpha Medical Honor Society. He has received both the Singer and Resident research awards for his original clinical research in neurosurgery. The Dystonia Association awarded Dr. Levine their Humanitarian Award in 2010 for his efforts in the treatment of dystonia.

**Stephen Grill, MD, PhD** is co-founder of the Parkinson's and Movement Disorders Center of Maryland, a freestanding clinic established in 2005. He has specialized in treating movement disorders since 1995. His research interests concern how use of sensory information and feedback may improve motor functioning in persons with Parkinson's disease and other movement disorders.

He received his PhD in Neuroscience from Northwestern University, Evanston, Illinois, and his MD also from Northwestern University at the Chicago campus. He completed his Neurology Residency at Washington University in St. Louis, Missouri, and a fellowship in Movement Disorders at the Human Motor Control Section of the National Institute of Neurological Disorders and Stroke of the National Institutes of Health, Bethesda, Maryland. Dr. Grill is currently an Assistant Professor at Johns Hopkins University (JHU) in Baltimore and Chair of the Medical Advisory Board of the Parkinson Foundation of the National Capital Area (PFNCA). In addition to his professorship at JHU and his PFNCA chairmanship, Dr. Grill participates in additional leadership roles, including Medical Advisor for the Greater Washington Support Group of the Dystonia Medical Research Foundation, and Medical Advisor for the Howard County Chapter of the National Ataxia Foundation. He is a member of the Society for Neuroscience and the Movement Disorder. He is the recipient of the Patients' Choice Award (2017, 2018). Patients' Choice recognition reflects the difference a particular physician has made in the lives of his/her patients. The honor is bestowed to physicians who have received near perfect scores, as voted by patients.



## Schedule for 2019

Upcoming Dystonia Support Group Meetings	Holy Cross Hospital 12:30pm 1500 Forest Glen DR, Silver Spring, MD
March 3, 2019 1:00 PM	Dr. Zachery Levine and Dr. Stephen Grill will speak on advances in Deep Brain Stimulation (DBS)
May 19, 2019 1:00PM	Andrea Schultheis, Occupational Therapist, Registered, Licensed, will speak on strategies for living better with dystonia to include positioning strategies.
September 15, 2019 10:00 AM to 3:30 PM	One Day Conference—Theme is Teamwork. Building your integrated team of specialists.
November 17, 2019	Let us know if you have ideas for this meeting.

### Mark Your Calendars—September 15, 2019 is Our Free All Day Conference

The conference will be held at Holy Cross Hospital. The theme for our all day conference is “Teamwork: Building your team to maximize your care”. We plan to have neurologists, physical therapists, personal trainers, clinical researchers, and many more. Lunch will be provided by Medtronic.

### Advocacy Day March 26, 2019 @ 12:00 pm - March 27, 2019 @ 6:00 pm

Westin Washington, DC City Center, 1400 M St NW, Washington DC 20005 and Capitol Hill  
You can help educate Congress on dystonia and the needs of the dystonia community. Your voice matters, your story matters.

Register at <https://dystonia-foundation.org/event/dystonia-advocacy-day/>

### Big Thank You for our NBC Health Expo Volunteers

We would like to thank the members who volunteered to staff our booth at the 2019 NBC Health Expo: Frank Presti, Hunter Webster, Kathy Shartzter, Virginia Foster and a very special thanks to David Wilson who braved the snow



storm and stayed the entire day on Sunday. We were able to provide information about the Dystonia Medical Research Foundation to an individual whose family member lives in Chicago and suffers from dystonia.

It made us feel great that we could offer such a rich resource for the gentlemen.





## Time to Renew Your Membership

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:

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