



Dystonia Support Group of Greater Washington DC

APRIL 2018

In Association with the Dystonia Medical Research Foundation

FROM OUR SUPPORT GROUP LEADER

At our March meeting, Dr. Codrin Lungu, a Program Director in the Division of Clinical Research at the National Institute of Health, National Institute of Neurological Disorders and Stroke, reported on the exciting research leading to better understanding of dystonia which will result in better treatments. Dr. Lungu led an active discussion for almost an hour after his talk, answering questions from the audience. He was asked about the study on zinc supplements that could possibly increase the intensity of the botulinum neurotoxin. Dr. Lungu explained results were inconclusive. The supplement was not strictly regulated and too much zinc is toxic. There are no additional research planned on the efficacy of zinc. He was asked about the study of Botox cream for the treatment of blepharospasm. Dr. Lungu explained the cream did not penetrate deeply. Patients were able to extend the time between injections. The manufacturer of the cream is refining the cream to penetrate more deeply. Dr. Lungu discussed Deep Brain Stimulation (DBS), explaining that the patient must weigh the risks against the benefits before undergoing such a procedure. Improvement after DBS is highly individualized and is not for all types of dystonia. After the discussion, we broke into small groups sharing our experiences with dystonia, the disease that brings us together.

Our May meeting promises to be another informative meeting. With the increased understand of the neuro-plasticity of our brains, the doctors of the Mid-Atlantic Brain and Neurological Rehabilitation Center will discuss concepts in clinical neuroscience related to rehabilitation of dystonia. This should be an extremely interesting meeting. Dr. Grill will be there for his interactive question and answer period.

We have begun to plan for all-day conference to be held November 4th. Please let us know of specific topics you would like included.

Our meetings offer an opportunity to meet others sharing a life time journey with dystonia. Please come and join us.

Always,

Sally

Sally Presti, Support Group Leader of the Dystonia Support Group of Greater Washington DC

Upcoming Dystonia Support Group Meetings	Holy Cross Hospital 12:30pm 1500 Forest Glen DR, Silver Spring, MD
May 6, 2018	Clinical Neuroscience Related to Rehabilitation of Dystonia Dr. Brice Jackson and Dr. Daniel Lane
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



Dystonia Support Group of Greater Washington DC Support Group Meeting May 6, 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: May 6th, 2018 Informal social starts at 12:30PM, Program starts at 1:00PM

1:00—1:15 Announcements—Sally Presti

1:15—2:15 **Dr. Brice Jackson and Dr. Daniel GJ Lane** will discuss **Clinical Neuroscience Related to Rehabilitation of Dystonia**. They will highlight a functional neuroanatomical understanding of the disorder, as well as present case studies demonstrating both efficacy and limitations.

2:15—2:30 Dr. Stephen Grill—Question and Answer Period

Speakers: **Brice Jackson, DC FACFM FABBIR** is a 2006 graduate of Life University in Atlanta, GA. He is a Fellow of the American College of Functional Neurology and a Fellow of the American Board of Brain Injury Rehabilitation. Dr. Jackson has been in private practice since 2006, treating children and adults with neurological problems such as autism, ADHD, concussion, chronic pain, migraine, dizziness, and vertigo. He and his staff are the exclusive provider of occupational therapy for the Virginia Institute on Autism.

Dr. Jackson has lectured and shared his experience in functional neurology with psychiatric facilities, public and private schools, occupational therapy facilities and parent groups in Virginia. Dr. Jackson is a member of the International Association of Functional Neurology and Rehabilitation, Virginia Chiropractic Association, the Charlottesville Chamber of Commerce, The Central Virginia Chapter of the Autism Society of America, and the University of Virginia Children's Hospital Committee.

In his spare time, Brice enjoys playing with his 4 children. He also enjoys reading, playing Ultimate disc golf, and hiking. Central Virginia is the perfect place to raise a family, indulge in nature's diversions, and maintain a healthy lifestyle!

Dr. Daniel Gerald Joseph Lane earned his Doctorate in Chiropractic as well as a Bachelor of Science from Logan College of Chiropractic where he graduated with Honors. In addition, he completed an Advanced Bachelor of Arts from the University of Manitoba in Canada. Subsequently, Dr. Lane continued with his post-doctoral and fellowship training and is now a board certified Functional Neurologist with degrees and/or certifications in numerous fields including: Board Certified Diplomate of the American Chiropractic Neurology Board (DACNB), Fellowship status of The American College of Functional Neurology (FACFN), and American Board of Brain Injury and Rehabilitation (FABBIR). He is a specialist in traumatic brain injury, concussion, and neurological therapeutic rehabilitation. Dr. Lane also holds certifications in Vestibular Diagnosis and Rehabilitation, Sports Chiropractic (CCEP), Whiplash and Brain Traumatology (Vehicular Crash), Soft Tissue (Graston, ART and others), Laser Therapy, and Fibromyalgia. Currently, Dr. Lane's academic ambitions would include other post-doctoral degrees in Functional Medicine, electrodiagnostics, and a PhD in Neurology.

Dr. Lane has been a keynote speaker, and provided many lectures/seminars for a host of institutions, companies, and other professionals. A brief list of these organizations would include the Holy Cross Hospital Neurology Department, Perdue Incorporated (National Nursing Conference), WBOC News, Peninsula Orthopaedics Associates and Peninsula Regional Medical Center, Regional Dental Association, Regional Dental Assistant Association, the Arthritis Foundation, TLC (Three Lower Counties) Community Services, and a host of other groups, events and associations. Dr. Lane is also a member of the Maryland Chiropractic Association, Chamber of Commerce, and a board member of Lower Shore Enterprises (LSE) which assists in providing employment and other services to individuals with disabilities.

Dr. Lane's passion is his wife, four children, and helping people via the employment of therapeutic neurological applications. He loves learning, and academia. Other interests include hiking, fishing and camping. As a former award winning competitive bodybuilder and personal trainer, he continues to enjoy all aspects of exercise and nutrition.

NBC HEALTH & FITNESS EXPO

Thank you to our volunteers that worked at our booth at the NBC Health & Fitness Expo. Many thanks to Irene Rudyj, Hunter Webster, Kathy Shartzter, Shidfar Shahriary, and Frank Presti.

DYSTONIA ADVOCACY DAY

On March 19 and 20, 2018 advocates from all across the country came to Washington DC to speak with their legislators on the following topics:

1. Provide the National Institutes of Health (NIH) with at least \$38.1 billion in FY 2019, a \$2 billion funding increase.
2. Provide the Centers for Disease Control and Prevention (CDC) with \$8 billion in FY 2019, a \$200 million funding increase.
3. Continue to include dystonia as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program for FY 2019. We are happy to announce, dystonia was included in the program for FY 2019.
4. Support the *Access to Marketplace Insurance Act* (H.R. 3976) which eliminates the restrictions that prevent charities from helping patients with chronic, costly, and life-threatening illness pay their medical bills.
5. Support the *Patients' Access to Treatments Act* (H.R. 2999) Treatments for dystonia are almost always placed in a specialty insurance tier, which forces disproportionate cost back on to patients and serves as a dangerous barrier to access.
6. Support the *Rare Disease Advancement, Research and Education (RARE) Act* which will improve rare disease awareness, education, research, surveillance, diagnosis, and treatment and to address common challenges faced by rare disease patients.
7. Oppose the passage of H.R. 620 *ADA Education and Reform Act of 2017* in order to protest elements of the Americans with Disabilities Act of 1990.

DYSTONIA MEDICAL RESEARCH FOUNDATION (DMRF) WEBSITE VIDEOS

Check out the videos that are posted on the DMRF website at <https://www.dystonia-foundation.org/>
The videos include

1. The Basics and the Latest: Overview of Dystonia and Treatments
2. Medical Therapies for Dystonia—Susan Bressman, MD
3. Surgical Treatments for Dystonia—Joan Miravite, NP
4. Occupational Therapy, Physical Therapy and Alternative Treatments
5. Dystonia in Children & Adolescents Webinar
6. How Will We Find a Cure? Dystonia Research Update
7. DMRF as Model—Drs Mahlon DeLong and Jan Teller
8. Reflections on DBS—Drs. Mahlon DeLong and Jan Teller
9. Dystonia Doesn't Respect Anything—Art Kessler
10. The Early Days of the DMRF and Today's Progress

DMRF'S LIST OF ONLINE SUPPORT

The Internet is a valuable resource to communicate with others in the dystonia community.

Online dystonia forums are support services that are available 24 hours a day, seven days a week to people all over the world.

DMRF's YouTube Channel

<http://www.youtube.com/facesofdystonia>

DMRF on Twitter

<http://twitter.com/dmrf>

DMRF on Facebook

<https://www.facebook.com/dystonia.foundation>

Facebook Group: "Cervical Dystonia Support Forum"

<https://www.facebook.com/groups/dmrf.cervical/>

Facebook Group: Oromandibular, Blepharospasm & Cranial Dystonia Support Forum

<https://www.facebook.com/groups/OMDBleph/>

Facebook Group: "20/30 Dystonia Group - A Forum for People in Their 20s and 30s"

<https://www.facebook.com/groups/2030dmrf/>

Facebook Group: "Support4Parents of Children with Dystonia"

<https://www.facebook.com/groups/support4parents.dmrf/>

Facebook Group: "Generalized Dystonia Support Forum"

<https://www.facebook.com/groups/dmrf.gen/>

Facebook Group: "Parenting with Dystonia Support Forum"

<https://www.facebook.com/groups/dmrf.parenting/>

Facebook Group: "Dystonia Spouses & Loved Ones"

<https://www.facebook.com/groups/dmrf.lovedones/>

Facebook Group: "Caring4Parents with Movement Disorders"

Email contact@dystonia-foundation.org for more information

DMRF Insights - Blog by Executive Director Janet Hieshetter

<http://dmrfinsights.blogspot.com/>

Dystonia & Special Education - Blog by Special Education Expert Roberta Senzel, Esq.

<http://dmrfspeciald.blogspot.com/>

"DBS for Dystonia" Yahoo Group

<https://groups.yahoo.com/neo/groups/DBSforDystonia/info>

Online Dystonia Bulletin Board

<http://www.dystonia-bb.org/forums/asd/>

Musicians with Dystonia Bulletin Board

<http://www.dystonia-bb.org/forums/mwd/>