



Dystonia Support Group of Greater Washington DC

September 2015

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 Dystonia Community,

Do you remember how frustrating it was to get a diagnosis and then try to explain to family and friends what dystonia does to you? Well, September is Dystonia Awareness Month and the Dystonia Medical Research Foundation (DMRF), which serves all forms of dystonia, is providing free "Dystonia Moves Me" kits to help get the word out about dystonia. Kits can be requested, free of charge, online at <http://www.dystonia-foundation.org/DMMkit> or by calling the DMRF at 312-755-0198.

At our next support group meeting on September 27th at Holy Cross Hospital, Dr. Stephen Grill, our support group's medical advisor, will speak on "Understanding Dystonia" which will include new information on the cerebellum's involvement, treatments, and the latest research. After a break, Dr. Grill will lead an open Question and Answer session to discuss topics related to the treatment and living with dystonia.

Our support group meetings are a wonderful opportunity for you to come and invite friends, family and caregivers (PT, OT, GP, etc.) to increase their understanding of dystonia and how it affects you. And as always, our meetings offer a place to informally meet others who are living with this frustrating disease. I believe with knowledge we have power.

Always,

Sally

2016 Support Group Activities

We need your advice on how to always be relevant and effective as a support group. Please take a moment to ponder these questions and call Sally Presti at 301-627-1657 or email Virginia Foster at dcdystonia.editor@yahoo.com

1. What activities would you like the support group to coordinate in 2016?
2. Do you want more or fewer meetings? We currently try to meet 4 times a year in March, May, September and November.
3. Do you want multiple speakers at our meetings?
4. What topics should our speakers address?
5. Do you want informal social gatherings, such as a get-together for brunch at a local restaurant? Locations?
6. Is Sunday afternoon the best time to meet? What time is best?
7. Do have suggestions for fund raising events?

We invite you to join our Core Group which meets four times a year to plan the meetings, topics, and activities for our support group. The next Core Group meeting is October 18, 2015, 1:30PM in Vienna/Annandale close to the Dunn Loring Metro.

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Dystonia Support Group of Greater Washington DC

Support Group Meeting September 27, 2015

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

When: September 27, 2015 Social starts at 12:30PM, Speaker starts at 1:00PM

Topic: **ADVANCES IN TREATING DYSTONIA**

Speaker: **Stephen Grill, MD, PhD.**

Parkinson's & Movement Disorders Center of Maryland

Medical Advisor to the Dystonia Support Group of Greater Washington DC

Dr. Grill will address the advances in dystonia including our understanding of it and treatment over the past 25 years. He will discuss the major advances which include:

- Understanding of the genetics,
- Understanding the pathophysiology
- Development of effective treatments including medication, botulinum toxin therapy and Deep Brain Stimulation (DBS)

If you like, bring a snack to share. Beverages will be provided.

Directions to Holy Cross Hospital 1500 Forest Glen Rd, Silver Spring, MD 20910-1484 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

PARKING: You may park free in the employee parking lot. Entrance to the employee parking lot is at the right of the hospital. Entrance will be opened from 12:00 to 2:00. You may exit at anytime.

Metro Directions to Holy Cross Hospital

Holy Cross Hospital is located five blocks from the Forest Glen (Red Line) Metro station. From the station, cross Georgia Avenue then walk five blocks down Forest Glen Road. Hospital is on the right.

CALENDAR OF EVENTS

WHAT	WHERE	WHEN	SPEAKER/TOPIC
Meeting of the Dystonia Support Group of Greater Washington DC	Holy Cross Hospital 1500 Forest Glen Road Silver Spring, MD 20910-1484	November 15, 2015 12:30PM to 3:30 PM	Janet Hieshetter Executive Director of the DMRF DMRF Research, Treatment, Education and Awareness
Dystonia Awareness Month	Anywhere our members are.	Month of September	Share your story. Get the word "Dystonia" out there.

BRAIN DONORS ESSENTIAL FOR IMPORTANT RESEARCH: Consider brain donation. For more information or to begin the registration process, visit <https://www.dystonia-foundation.org/get-involved/participate-in-research/become-a-brain-donor> or contact the DMRF at 800-377-3978.

STAY IN TOUCH: Sign up for the DMRF monthly e-newsletter for the latest updates and announcements at <https://www.dystonia-foundation.org/get-involved/stay-connected> or contact the DMRF at 800-377-3978.

NEWS YOU COULD USE

Programs Provide Brand Name Medications at No or Low Cost to Eligible Patients

The NeedyMeds website provides a list of Patient Assistance Programs that provide brand name medications at no or low cost to eligible patients. These program are provided by various pharmaceutical companies and each program has different eligibility requirements. For further information, visit the NeedyMeds website is at <http://www.needyeds.org/pap> or call the telephone numbers provided for each program.

BOTOX PATIENT ASSISTANCE PROGRAM—Provides brand name medications at no or low costs.

Provided by: Allergan, Inc. P.O. Box 1370 San Bruno, CA 94066 Tel: 800-442-6869, opt 4

ELIGIBILITY REQUIREMENTS:

Insurance Status— Must be uninsured or underinsured

Those with Part D Eligible? — No

Income— At or below 300% of Federal Poverty Level (FPL)

Diagnosis/Medical— Criteria Diagnosis must be supported in Comendia

US Residency Required? — Must reside permanently in the US or Puerto Rico

BOTOX SAVING CARD—This is a discount card program.

Provided by: Allergan, Inc. P.O. Box 1370 San Bruno, CA 94066 Tel: 800-442-6869, opt 4

Commercially insured patients meeting the eligibility with cervical dystonia or upper limb spasticity can receive up to \$500 per treatment. All other patients receiving BOTOX for an FDA-approved indication can receive up to \$100 per treatment. The prepaid card is only good toward your out-of-pocket expenses for BOTOX treatments.

ELIGIBILITY REQUIREMENTS:

Insurance Status— Must be commercially insured

Those with Part D Eligible? — No

Income— Not disclosed

Diagnosis/Medical— FDA approved diagnosis

US Residency Required? — Must reside in the US

MYOBLOC REIMBURSEMENT SUPPORT PROGRAM—Provides brand name medications at no or low costs.

Provided by: Solstice Neurosciences, LLC 4700 Millenia Blvd., Suite 310, Orlando, FL 32839 Tel: 888-461-225, opt. 3

ELIGIBILITY REQUIREMENTS:

Insurance Status— Not specified

Those with Part D Eligible? — Not specified

Income— Not disclosed

Diagnosis/Medical— Medically appropriate condition/diagnosis

US Residency Required? — Must be a citizen

XEOMIN PATIENT SUPPORT PROGRAM—Provides brand name medications at no or low costs.

Provided by: Merz Pharmaceuticals, PO Box 4280, Gaithersburg, MD 20885-4280 Tel: 888-493-6646, opt 2

ELIGIBILITY REQUIREMENTS:

Insurance Status— Must be uninsured or underinsured

Those with Part D Eligible? — No, must be ineligible

Income— Not disclosed

Diagnosis/Medical— FDA-approved diagnosis or authorized compendia listing

US Residency Required? — Must be citizen or legal resident

XEOMIN PATIENT CO-PAYMENT PROGRAM—This is a co-pay assistance program.

Provided by: Merz Pharmaceuticals, PO Box 4280, Gaithersburg, MD 20885-4280 Tel: 888-493-6646, opt 2

ELIGIBILITY REQUIREMENTS:

Insurance Status— Must not have public insurance, may have private insurance

Those with Part D Eligible? — No

Income— No limits

Diagnosis/Medical— Not required

US Residency Required? — MA residents are not eligible

ACUPUNCTURE AND CHINESE HERBS

Topic Presented by Leanne Ekstrom at our May 31, 2015 Support Group Meeting

At our last support group meeting on May 31, 2015, Leanne Ekstrom spoke on Acupuncture and Chinese Herbs and how the inclusion of these modalities into your wellness plans can be beneficial. In order to "demystify", she explained the key theories of Chinese Medicine practice and reviewed some research on acupuncture/herbs and dystonia. Her summary of her presentation is as follows.

One challenge when communicating about Chinese Medicine to groups is that each acupuncture treatment and herbal formula is customized to each person so being very specific when talking to a group is impossible. Even amongst individuals with the same Western medical diagnosis, in Chinese Medicine each person is treated in a customized manner to them. In Chinese Medicine we look at the whole of you. And each of you here are different from one another even though you also have things in common. So, I am going to have keep my talk very general because talking about specific acupuncture treatments or herbs is really not productive because what might be appropriate for you would not be appropriate for someone else.

Acupuncture and herbs support you as a whole person - from your emotional state (if you tend to feel angry, sad, happy), to whether you tend to be constipated or have diarrhea, to if you feel hot or cold, to your sleeping pattern, to the location where you have physical symptoms ...essentially we look at the whole of you and from there piece together how best to support you both emotionally and physically. The emotions and the body are not separate. Each acupuncture point works on an emotional level as well as a physical one. The emotions were never separated from the body in Chinese Medical Theory. So what can you get out of acupuncture and herbal therapy? Not a miracle cure – but I am saying that acupuncture and herbs can help you feel better in some way, be it pain relief, potentially increased mobility, or simply sleeping and digesting better. And your care takers need to be taken care of too.

Acupuncture is not only good for "sick" people. Historically acupuncture was a preventative medicine and the village doctors only got paid if the town was healthy.

So, first let's explain a bit about acupuncture.

WHAT IS AN ACUPUNCTURE CHANNEL AND AN ACUPUNCTURE POINT? The diagram on the next page, entitled Acupoints of Traditional Chinese Medicine, depicts the Acupuncture Channels and Points with the markings on the bodies.

Question 1: what are the lines on the body? Those are the Acupuncture Channels! Not all the Channels are on that picture – there are many more and they penetrate the body so they are not all visible there! Western Science has yet to "discover" what the Channels are physically BUT in Chinese Medicine the Channels are very clearly defined lines of energy that flow in relationship to very specific body landmarks. In clinical practice, it is very common for me to needle a point on a channel and have the patient report feeling sensations elsewhere along that same channel.

Leanne Ekstrom is a Licensed

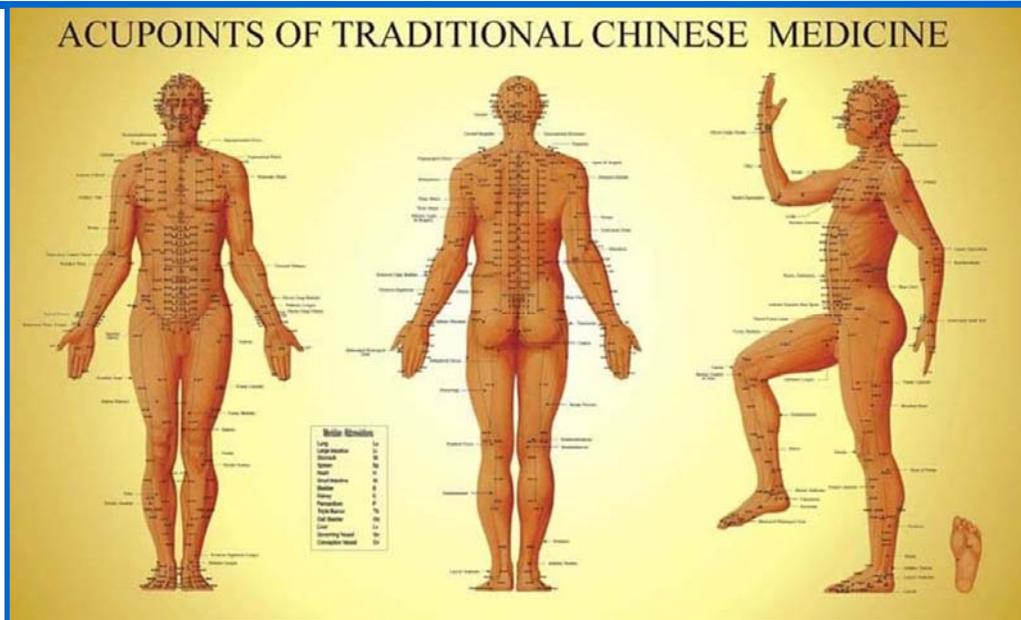
Acupuncturist and Chinese Herbalist in Washington, DC.

The educational requirements to become an Acupuncturist and Herbalist include completing a 3 year Master of Acupuncture degree and an additional 2 year Chinese Herbology certification. Prior to studying Chinese Medicine, Ms. Ekstrom attended The George Washington University where she earned her B.A. in Sociology and Public Health. She then went to The University of St Andrews in Scotland for a Masters degree in Health Geography/Health Research Methods. Ms. Ekstrom then worked as a Research Assistant for the Center for Mind Body Medicine and also for the late Dr. Candace Pert, a Neuropharmacologist. She currently practices Chinese Medicine in downtown Washington, DC at 910 17th St NW; Suite 1020 20006. Her website is www.EkstromAcupuncture.com and her email address is Leanne@EkstromAcupuncture.com



ACUPUNCTURE AND CHINESE HERBS

Continued



Depiction of the Acupuncture Channels and Points with the markings on the bodies.

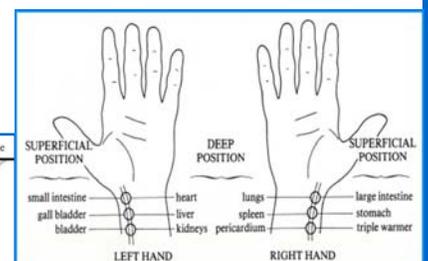
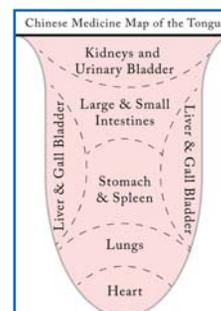
Question 2: What do the Channels do? The Channels are each responsible for specific body functions. Each Channel also has a relationship with certain organs and areas of the body. When there is an imbalance in a particular Channel, the Channel does not function optimally and symptoms, including pain, appear. All Channels have a relationship to one another so when one goes haywire, others go bonkers too. These symptoms that appear when the Channel is in distress are called Patterns of Disharmony (our prettier word for diseases). The Patterns of Disharmony are very clearly defined clusters of symptoms. Poor diet, fast lifestyle, physical trauma, being exposed to pathogens, and intense emotions can all lead to mayhem.

Question 3: What are those dots along the lines? Those are the Acupuncture Points! Just like the Channels have specific functions, there are very clear “pit stops” along the Channels where Acupuncture Points are found. Each point has a defined function that is related to the Channel function but more specific. By simulating these points with needles, heat, or pressure, I can encourage the point to increase its function or to decrease its function. This increasing effect is called Tonifying and the decreasing effect is Dispersing. Tonifying and Dispersing are performed using various needling techniques.

Question 4: How do you know what to do? Aside from listening, Pulse and Tongue are crucial.

Listening to the pulse refers to when the practitioner places their fingers on certain spots on your wrist over your radial pulse and feel for certain qualities at each of the positions and each of the levels. It takes a long time to develop the skill.

The tongue is an internal organ that can be seen and different parts of the tongue are associated with different channels and organs. Before an acupuncture appointment do not brush your tongue because we look at 1)if it deviates 2)if there is a coating 3) the color of the body of the tongue) any cracks or spots on the tongue.... The shape of the tongue. It all has meaning.



ACUPUNCTURE AND CHINESE HERBS

Continued

Research: Many people in the United States think of acupuncture for pain relief, but really it can assist with any health concern. Acupuncture is well known (and has been well researched for over 2,000 years), to help ease all types of pain conditions. There are a number of current studies on its effectiveness for pain in many conditions - and the military is actually funding a large amount of research on how acupuncture can help with the emotional and physical pains returning soldiers are dealing with.

In many of the research studies on acupuncture, the trials are set up in a way that does not reflect how acupuncture is actually practiced. In the trials, each patient is given the same treatment and the same acupuncture are used – when in real life that does not happen. I just ask, when you look at acupuncture studies, be mindful that the results from the trials might not accurately reflect the effectiveness of acupuncture.

Research Specific to Dystonia: Effectiveness of acupuncture in cervical dystonia.

Acupunct Med. 2010 Jun;28(2):94-6. doi: 10.1136/aim.2009.002048.

Deepak R¹, Mathew H, Koshy M.

Abstract

This case describes the successful addition of acupuncture to treat a patient with cervical dystonia previously managed with Botox (botulinum toxin) injections. This resulted in reduced pain and muscle spasm relief and to the authors' knowledge is the first case to be reported using this treatment combination. The patient was diagnosed with the idiopathic variant of cervical dystonia and had been treated with regular Botox injections for almost a year and half. She was then referred for a course of acupuncture to manage pain and reduce excessive muscle tone. She had excellent benefit from the acupuncture and she continued to get top-ups of acupuncture every 8-10 weeks. Requirement for Botox injections had decreased thus reducing its long-term side effects.

PMID: 20615862 [PubMed - indexed for MEDLINE]

Research Specific to Dystonia: Effectiveness of acupuncture on regional cerebral blood flow.

Ann Nucl Med. 2006 Jan;20(1):83-7. Acupuncture-induced cerebral blood flow responses in dystonia.

Ha-Kawa SK1, Yoshida T, Yague T, Tani M, Suzuki T, Sawada S.

OBJECTIVE:

The effect of acupuncture on regional cerebral blood flow is unclear. Single-photon emission computed tomography studies on three patients with dystonia were performed before and after acupuncture treatment to test the contention that acupuncture affects regional cerebral blood flow.

METHODS:

Regional cerebral blood flow images were evaluated bilaterally in five areas related to the pathophysiology of dystonia (1, superior frontal; 2, middle and inferior frontal; 3, primary sensorimotor; 4, lenticular nucleus; and 5, thalamus). More than 10% left-right asymmetry in regional blood flow over three continuous slices was defined as significant laterality. Post-Acupuncture blood flow and laterality were evaluated with the pre-Acupuncture blood flow study acting as a control in each subject.

RESULTS:

The clinical effect of ACP was remarkable in all patients and regional cerebral blood flow increased in most segments. Pre-acupuncture regional blood flow exhibited significant laterality in eight segments of the three patients. Laterality reversed in seven of these segments and resolved in the remaining segment after acupuncture. Pre-acupuncture regional blood flow laterality was not preserved in any segment after acupuncture. The remaining five segments exhibited laterality only after acupuncture. In total, after acupuncture 13 of 15 segments demonstrated a change in cerebral blood flow that was greater unilaterally.

CONCLUSIONS:

Acupuncture results in an increase in regional cerebral blood flow that is greater unilaterally. We think that unilateral change in cerebral blood flow may be correlated with the action of ACP on the central nervous system in patients with dystonia.

ACUPUNCTURE AND CHINESE HERBS

Continued

History of Chinese Herbs:

First, the character used for herb is composed of two parts the top parts are grass or plants and the bottom part means music, also happiness. So herb is music or happiness in plant form.

And, just as music, Chinese herbs in a way work through a resonance with your body to realign it. Just like when you play a musical note like a D and the D string on another instrument close by will vibrate. There is a resonance with the body.



So, the history.

In pre-history, so before 1000BC, Shen Nong, who was the founder of Chinese agriculture, “tasted the flavor of the myriad plants and the sweetness or bitterness of the springs, letting people know what to avoid and what to use as remedies. He encountered 70 medicinal substances in a single day.”

168 BC – a tomb from this time contained a text that used 400 substances from plants, animals, minerals as medicinals and formulas for topical applications and ointments.

The first text that has been used continuously since creation is the Shen Nong Ben cao in which 365 medicinal substances were grouped into 3 hierarchical grades corresponding to heaven, human and earth. Heaven could be taken over long periods of time with only beneficial effect. Human grades could be taken for somewhat longer periods but were used for preventing illness or counterbalancing depletions. The lowest, the earth, were used when someone was sick for a short period of time.

In 657-659 AD the Tang Dynasty created government sponsored material medical texts. This study of herbs carried on through the Song Dynasty 907-1276.

Formulary from the “Pharmacy Service to Benefit the People” in 1217 was a text coming from the state.

Again, observation over thousands of years has given us the knowledge to use the herbs in a safe and effective way. Herbs are always used in conjunction with other herbs. In present day research, one plant is taken out of a formula to be studied but of course that isn’t going to be effective. It is the group of herbs working together that enhance each others effects or mitigate potential side effects. Its like a symphony. If you only listen to the oboe of course its not going to work.

Safety and efficacy: There are cautions, which is why you should **not self-prescribe**. A few years back there was hullabaloo about ephedra. First of all, anyone with knowledge of Chinese herbs would know that certain people should never use ephedra. Second, the dose that was given to people for weight loss was CRAZY! Like 1.5g to 3g is used in formulas. Not 30! Also, in the few formulas ma huang is in, there are other herbs to reduce toxicity AND it is often used in only 1 or 2 doses. Never long term. The quality is another factor but there are well known importers who independently test what they are receiving and with raw herbs – part of the training of being an herbalist is plant identification.



The education requirements to be an acupuncturist here in the US is a 3-4 year graduate degree, that obviously includes 250 treatments that you have to do under supervision. Also, to be an herbalist is it another 2 years. To practice in DC or Virginia you have to pass the three National Board exams. In Maryland, the board exams are optional. They just require certain academic requirements.

But then of course most people find mentors – and there is always continuing education.

In finding a good acupuncturist I think one key component is rapport. Having patience is key because acupuncture and herbs are a slow medicine and a commitment. It is not a “one walk dog”. Regular treatments are best.



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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- **Virginia Foster**
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Dcdystonia.editor@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

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