



Myositis Newsletter



THE MYOSITIS ASSOCIATION

North Georgia / Atlanta Support Group

Save the Date!

Our next meeting will be held **Saturday, January 18, 2014**. Our guest speaker, **Dr Murta Cassoobhoy MD, FACP**, will be speaking to us on different aspects of Medical Emergency Readiness.

Dr Cassoobhoy attended Medical School at Wake Forest and Residency at Emory University. He is an Emergency Medicine Specialist and has over 14 years of experience in Internal Medicine, Hospice and Palliative Medicine and Sports Medicine.

Jot down any questions you may have and join us to hear Dr Cassoobhoy.



Dr. Cassoobhoy MD

2014
Meeting Dates
January 18
April 5
August 9
October 11

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Special points of interest:

- *Save the date, Jan 18 for the next meeting.*
- *Dr Cassoobhoy to speak on Emergency Medical Readiness.*
- *H.P. Acthar Gel for DM & PM and Financial assistance information.*
- *2013 Conference Update*
- *Helpful websites*

Past Meeting Information

We had our largest turnout ever for our Autumn Meeting on September 7th, with over 60 current and several new members attending. Thank you all for making this meeting such a success!

Our speaker was **Mr. Gary Hogge, DVM, MS, Ph.D**, Vice President, Medical Affairs with Questcor Pharmaceutical, manufacturer of H.P. Acthar Gel. Mr. Hogge spoke to us on the success that Acthar Gel is having on some patients with dermatomyositis and polymyositis. Acthar, an older medication, having been developed in 1952 is the *only* FDA-approved drug for DM and PM. It is given by subcutaneous injection. For more information, visit www.acthar.com.

Several of our members have taken, or are still on Acthar. If your doctor has suggested taking it and you would like to speak to them, please contact Cheryle at 678.386.3435

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Financial Assistance for Acthar

Acthar Support & Access Program(ASAP)

The Acthar Support & Assistance Program provides assistance with insurance authorization and copayments. This no-cost service aims to help patients with all aspects of their Acthar treatment including cost, delivery, injection training and more. For more information visit www.acthar.com and click on the Acthar Support & Access Program or phone 888.435.2284.



Chronic Disease Fund (CDF)

In addition to the Acthar Support and Access Program, the Chronic Disease Fund also works closely with healthcare providers, including specialty pharmacy, to provide immediate access to financial assistance for expediting therapy management. They currently have funding for patients with Dermatomyositis and Polymyositis to assist in obtaining the FDA approved drug H.P. Acthar Gel. If you have insurance they can assist with co-pay if your are financially eligible. If you have no insurance, they offer free drug programs. Enrollment is easy and approval is almost immediate.

Find more information at www.cdfund.org or call 877.968.7233

Helpful and Reliable Websites

www.drugs.com

This site is full of useful information. It lists drugs from A-Z, but also has a pill identifier, to help you determine if that different looking generic tablet by a different manufacturer, really is the same as the one previously prescribed. Under the Interactions Checker, you can list all your current medications to see if there are interactions you should be aware of.

www.mayoclinic.com

One of the most respected sites that gives patients reliable information.

www.labtestsonline.org

This site is noncommercial, peer reviewed and patient friendly. Search lab tests, conditions and diseases.

www.igliving.com

IG Living is an award winning magazine dedicated to giving support and information to patients taking IVIG. You can read the current & past issues online or you can request a print version subscription be mailed to you.





Conference Recap

This years annual patient conference and **The Myositis Association's 20th anniversary celebration**, was held **October 17th-20th** at the beautiful Marriott Downtown , Louisville, KY.

Most of the educational sessions were presented by members of TMA's medical advisory board. Nearly all of the presentation power points are available online at www.myositis.org The sessions covered many different aspects of myositis. Nutrition for Inflammatory Disease, Myositis and Your Lungs and The Role of Genetics in IBM, just to name a few. Please go online to read these informative sessions.

Augie will give a more detailed recap at our January 18th meeting.

The **2014 Conference** will be held **September 4th-7th, 2014** at the Peppermill Resort in the "*Biggest Little City in the World*", Reno, Nevada.

Book Review

Doctor, Your Patient Will See You Now

Gaining the Upper Hand in Your Medical Care

Steven Z Kussin, MD

This book, written by a physician after he was hospitalized, offers invaluable advice on how to protect your health within the healthcare system. It teaches one to be savvy and become your own best advocate to receive the best healthcare possible, both at your physicians office as well as when you are hospitalized. Section V of the book, Hospital Dangers and How to Prevent Them is alone worth the price of the book, teaching the reader on how to avoid medication errors and hospital acquired infections.

To quote Dr Kussin....patients can no longer acquiesce in their health care or submit to the doctors that attend to it. Patients must take part in and, in fact be in charge of their medical care and thereby their own destiny. Our penchant for "whistling by the graveyard" may still be understandable, "whistling by the doctor's office" now carries a steep price.

Doctors Business Cards

Cheryle is starting a database of rheumatologists and neurologists in our area. This will be especially helpful for newly diagnosed members and also for those who aren't completely satisfied with their current doctor. If you have a really good primary doctor and would like to share his or her information as well, pick up an extra business card or two and bring them to our January meeting.



North Georgia / Atlanta Support Group

CheryleMiller
301 Cannon Farm Road
Oxford, GA 30054
CheryleMiller@comcast.net

Questions on myositis? Please call:
DM ...Mary Root 404.625.2210
IBM ...Augie 678.358.6266
PM ... Cheryle 678.386.2435



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www.myositis.org



Volunteers Needed

If you would like to help out with our meetings, it would be greatly appreciated. We currently need volunteers to bring items such as bottled water and cookies, brownies or fruit for our January meeting. Call or email Cheryle. Phone 678.386.2435

Quote on Friendship

“How many slams in an old screen door? Depends on how loud you shut it. How many slices in a bread? Depends on how thin you cut it. How much good inside a day? Depends on how good you live 'em. How much love inside a friend? Depends on how much you give 'em.”

... Shel Silverstein



Our Beginning

When I was diagnosed in the fall of 2006, I discovered there were no support groups in the entire state of Georgia! Unbelievable! I felt so very alone with this disease. I had family and friends who loved me and cared for me, nursed me in and out of the hospital. But I wanted more. I wanted to get to know others with my condition and to speak with other people who truly understood what I was experiencing.

Late in the summer of 2009, I was still quite ill with polymyositis and my subset conditions of poly-inflammatory arthritis and pulmonary fibrosis. Then I met Mary Root. Mary has dermatomyositis and unfortunately pulmonary fibrosis too. We met at a Pulmonary Fibrosis Support Group meeting held at Emory. She and I quickly became friends and together we decided to start a support group for myositis. My biggest fear was that I would be ill at meeting time and have to cancel, but I knew with Mary along side me that it would all work out and together we could do it. Thanks, Mary for all that you do.

We had our first meeting September 2009 with 11 in attendance. My goodness how we've grown! Yet, I know there are still so many who don't know about us. I think our goal for this new year, 2014 should be for each of us to get the word out to our doctors & let them know about our group. They in turn, can inform other patients about our group. I will have flyers to hand out at the January Meeting. If you have a suggestion or an idea on a way to reach others, please give me a call. Meeting information and lunch reservation forms will be sent out two weeks prior to our next meeting. See you there, Cheryle

Merry Christmas and a Happy New Year
