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\$5.00**

Put your shoes on without having to bend over.

In the picture, Frank, has to bend a little, but then he is 6'1". I'm 5'3" and don't have to bend at all! I wish I had had one when my muscles were at their worst.

Proceeds will go to TMA towards research to fight myositis.

Taking orders now for delivery at the next support group meeting.

To order, call Cheryle at 678.386.2435 or Email: CheryleMiller@comcast.net

**Save The Date!**

Our next meeting will be held **Saturday, May 9<sup>th</sup>**.  
Physiologist **Avril James-Hurt**, to speak on 'What is Mindfulness?'

**January 24' 2015 Meeting Recap  
What a great meeting!**

We had 29 members attend, including one new member. Gail Edwards (PM) along with her friend, Maxine Cross, joined us from Tyrone, GA. Welcome to our group, ladies. Others who traveled far and wide were Joel Mayo (PM) from Hayesville, NC, Nancy Gelpi (PM) and her father, Tim Collins (DM), drove from Augusta for their second meeting with us.

Unfortunately, many members were out of town. In our attendance breakdown, we typically have IBM members with the largest number, and PM members the smallest, but this meeting certainly was an exception. The breakdown was 3 IBM, 6 DM and 12 PM.

**Speaker Presentation Highlights:**

Our speaker was Board Certified Rheumatologist, **Dr. Glenn Parris, M.D.** of Parris and Associates in Lawrenceville. Dr. Parris gave a remarkable and interesting presentation. He covered several aspects of living with myositis. He stated how auto-immune diseases are all the same in attacking our own 'self', but can manifest differently in each person. For example, some patients never show antibodies or a high CPK in their lab work. Other methods, such as C Reactive Protein (CRP) and a muscle biopsy for example, are needed to monitor levels of inflammation and muscle deterioration.

Some myositis patients can gradually develop an overlap of one or more other auto-immune diseases. For example, some develop an inflammatory arthritis or Sjögrens Syndrome that has symptoms that include dry eyes and mouth. Others develop Scleroderma or Lupus. When these overlaps occur with myositis, they are collectively, what is known as Mixed Connective Tissue Disease (MCTD).

*The first line of defense* in treatment to slow down the inflammation in our bodies, is of course, the steroid Prednisone. It's the drug that most of us have had a 'love / hate' relationship with.

*The second line of defense* are chemotherapy drugs such as Methotrexate or Cellcept, that are taken to allow us to reduce and taper down the high doses of Prednisone to alleviate the damaging effects.

*The third line of defense* is typically intravenous immunoglobulin, also known as IVIg. Although not a medication, it is manufactured from a refined pool of human plasma. It too, can have serious side effects such as renal failure or aseptic meningitis.

Continued on the next page.

## January 24 2015 Meeting Recap Continued

Other strategies for treatments include Anti-TNF therapies such as Remicade (infliximab) and Humira (adalimumab) or Biologic Drugs such as Rituxan (rituximab). Plasmapheresis (Plasma Exchange) that will 'clean' the blood is another option. One 'new' drug that that is actually an old drug, that many are doctors are now using to treat myositis, is H.P. Acthar Gel. Acthar was developed in the early 1950's, and has actually been around longer than Prednisone. It is the only FDA approved drug for DM and PM.

Dr. Parris stated that we need to be cautious regarding taking statin drugs, as they can cause muscle weakness. If your primary doctor suggests that you take a statin, be sure to discuss it with your rheumatologist first.

After the presentation, Dr. Parris has a **Q & A session**. Here are a few of the questions.

Q. Is turmeric a good supplement to take?

A. Turmeric has an anti-inflammatory component, but doesn't get into our bloodstream in any useful amount, because of the way it is processed in the gut.

Q. Is taking creatine helpful?

A. It can be useful, but the body cannot use it until the inflammation is under control..

Q. Should I get a Shingles Vaccine?

A. The shingles vaccine, Zostavax, is a live virus. DO NOT take a live vaccine if you are taking immunosuppressant medications

Dr. Parris sees approximately 40 myositis patients, most of whom have DM or PM, but only has a few IBM patients. He is currently taking new patients, but has approximately a 3 month wait for a new patient's first appointment. His colleague, Dr. Samakur, D.O., is able to see new patients much more quickly. In fact, two of our relatively new members, were recently each in dire need of a new doctor, were able to get appointments within a week. Bravo Dr. Samakur! You can reach either doctor at **770.962.1616**.

## Second Group

During the meeting we also discussed the formation of a 2<sup>nd</sup> support group in the Atlanta area. No further details are known at this time.

## Conference Calls

Conference calls are in the planning stages, for those to ill or too far away to attend the meetings. The first call for those with DM, will be held in early April. After that, I will be holding one for PM, then last but not least, IBM. If you are interested in participating, please let know. Participant space is limited and if we get too many for one call, I will keep a waiting list for the next call. [CheryleMiller@comcast.net](mailto:CheryleMiller@comcast.net) or 678.386 2435

## Smile.Amazon.Com

Do you shop at Amazon.com? Then consider signing up with Smile.Amazon.com. Each time you make a purchase, a small donation (.5%) will be made to help fight myositis. On your first visit to the website, Smile.Amazon.com, you will be asked to choose a charity. The Myositis Association is listed as Myositis Association of America. What an easy way to help make a difference!!

## Calcium Absorption

Many of us have been instructed by our doctors to take Calcium supplements. Do you also take a proton pump inhibitor? PPI's include Nexium, Prilosec, Prevacid, Aciphex, Protonix and Zegarid. When taking one of these drugs, your stomach acid is reduced, thus limiting your ability to absorb regular calcium. Calcium Citrate is a form of calcium that does not need stomach acid for our bodies to digest.

## TMA Live Discussions

Upcoming Q & A Session

### Lung Disease and Myositis

Dr. Dana Ascherman

March 9<sup>th</sup> at 3:00pm

You may submit your questions to the doctors in advance of the session at [www.myositis.org](http://www.myositis.org)

The transcript will be available to read afterward, if you can't log on to the live session. Past session transcripts are also available.

As a member of TMA, you will get notice in advance of all Live Discussions.

Join today, it's free!

## 2015 Annual Patient Conference At the Caribe Royal in Orlando, FL

September 10-13<sup>th</sup>

Registration is now open.  
Details at [Myositis.org](http://Myositis.org)

Want to go, but your funds are limited?  
You may be eligible for a scholarship for the conference portion.

Charlia is keeping a running list of those who would like to apply.

Email her at:

**[Charlia@myositis.org](mailto:Charlia@myositis.org)**

## February 28th is Rare Diseases Awareness Day



### EZ-Step

Under new ownership &  
available once again!

This device makes it possible to use the stairs, when it isn't possible to lift your foot more than just a few inches.

[EZ-Step.com](http://EZ-Step.com)

## Pixie Allison is the new co-leader for our group.

Due to family illness, Mary Root has had to relinquish her position as my co-leader. She will still attend meetings as she finds it possible to do so. Let's all send her good wishes and lots of prayers.

Pixie has been a long time member of TMA and was involved in support groups in New York and Texas. When I approached her and asked if she might be interested in assisting me as co-leader, she graciously accepted. Please welcome her as she becomes my new sidekick. I think we will make a great team.

*They say Spring is just around the corner.*

I haven't yet found that corner, but I wish you Happy Spring, for when it does arrive!

Cheryle Miller

678.386.2435 or [CheryleMiller@comcast.net](mailto:CheryleMiller@comcast.net)