



# Myositis Newsletter



THE MYOSITIS ASSOCIATION

## Georgia Myositis Support Group Newsletter

Volume 19, Issue 2

*~Next Meeting~*

**November 9, 2019**

**Gwinnett Library, Collins Hill**

**455 Camp Perrin Road, NE**

**Lawrenceville, GA 30043**

**10:30am-100pm**

**Due to a shorter meeting time,**

**No Lunch this meeting**

***Speaker To Be Announced***

Have questions? Call 678.386.2435

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

More details will be emailed in October.

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Please plan to attend our next meeting on Saturday, November 9th. It has been increasingly difficult to secure meeting space at either Collins Hill or Five Forks Libraries and this is the only time slot available. We thought this Fall we would be in our new space at the community center at Covenant Presbyterian Church, but they have had a delay and now expect it to be ready in April. That will be a really good location for us, not far from where we meet now at the Collins Hill Library and quite close to the Mall of Georgia & I-85.

Next meeting is planned for late January

If you have a change in your address, phone number or email

Please contact Cheryle

**678.386.2435**

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## The 2019 Annual Conference

TMA's 2019 Annual Patient Conference was another amazing event! Each year the Conference provides those who live with myositis the opportunity to gather to learn about their disease as well as to meet and share experiences with others who understand their challenges.

Nearly 500 people attended from all over the US as well as folks from Canada and Europe, nearly half of whom were first-time attendees. They participated in nearly 90 educational and support sessions focused on the theme of "Who you are matters," offering insights that address individual differences in myositis diseases.

The Conference kicked off with a representative from Senator Amy Klobuchar's office welcoming us to Minnesota. Outreach Director Sarah Franz provided an update on Senator Klobuchar's extraordinary efforts on behalf of those who live with rare diseases like myositis as co-chair of the Congressional Rare Disease Caucus.

Psychologist Mary E. Siegel, PhD, coauthor of *Sick and Tired of Feeling Sick and Tired*, offered a keynote address on a topic near and dear to those with myositis: "Living with Invisible Chronic Illness." Throughout the Conference, myositis experts from TMA's distinguished Medical Advisory Board not only offered talks but generously spent extensive time responding to individual questions from attendees.

In addition to disease-focused talks, this year's Conference program addressed several new areas of interest. Mental health was a particular focus, with sessions allowing individuals to share issues related to psychological concerns as well as a panel of mental health experts offering resources and advice. Several sessions also focused on the needs of care partners, including several sessions addressing emotional needs as well as demonstrations of how to manage their loved one's physical needs.

Conference sessions also offered practical skills for those who want to help TMA spread awareness of myositis. Workshops were available to learn how to start a TMA support group, how to more effectively tell your myositis story, how to fundraise, and how to advocate for public policy changes. A panel of experts also discussed how those who live with a rare disease can advance the search for a cure by participating in clinical trials.

The Conference was not all work, however. A wine and cheese reception, held on Thursday evening, encouraged attendees to "show their stripes," a reminder of the saying that rare disease patients are as uncommon as zebras. TMA provided attendees with travel tips with the assistance of a certified accessibility travel expert who has over 25 years of experience in the field. Many lasting friendships were made through networking opportunities as attendees dined with others from their own geographic locations and met others with their type of myositis.

If you weren't able to attend this year's Annual Conference, we hope you will consider joining us next year. (The location is not yet finalized, but we will let you know soon where it will take place.) You can also see slides and videos from many of this year's talks posted online.

The 2019 Annual Patient Conference would not have been possible without the generous support of our sponsors, including our platinum sponsor, [Mallinckrodt Pharmaceuticals](#), and gold sponsor, [CSL Behring](#).

TMA would also like to thank [CSL Behring](#) and Dr. Robert Wortman for sponsoring the 2019 Myositis Medical Symposium where myositis experts from our Medical Advisory Board shared current research results with healthcare professionals. The Symposium took place on Friday during the Annual Patient Conference.





# Products That Benefit

## Gillette Treo

*Of special interest to caregivers!*

Gillette has designed **a razor with built-in shave gel**, designed specifically to shave someone else. It was designed with caregivers for caregivers to use. Treo has a safety come that helps protect the skin and to prevent clogging, an ergonomic handle and contains a special non foaming gel that hydrates the hair with no water required.

Purchase online and get free shipping.

For more information, go to [www.gillette.com/Treo](http://www.gillette.com/Treo)



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## MyMedSchedule Mobile

*Free app available for smart phones*

MyMedSchedule allows you to create and save easy-to-understand medication schedules. Each MyMedSchedule shows what times you should take your medications or supplements, how much to take, and the purpose. You can set up text and email reminders for reminders to take your meds. With these reminders you never forget a med. MyMedSchedule Mobile is in sync with MySchedule.com, a free website, so it can be easily revised, accessed and printed from anywhere in the world, and you can quickly have an updated schedule for an emergency or routine doctor visit. Now your specialists can be aware of all the medications you are taking and you can access MyMedSchedule from your mobile phone or any computer around the globe.

**MyMedSchedule**  
 MyMedSchedule.com  
 Revised: 7/23/2011 at 9:53 AM  
 Jane S Doe DOB: 12/21/1950 Family Doctor: Dr. B. Smith  
 Allergies: Penicillin 908-355-5355

| Take These Medications                                                                                     | At These Times |           |            |           |                              |
|------------------------------------------------------------------------------------------------------------|----------------|-----------|------------|-----------|------------------------------|
|                                                                                                            | 7am            | 8am       | 9am        | 12N       | 8pm                          |
| <b>Atace<sup>®</sup></b><br>(Ramipril)<br>2.5 mg Capsule(s)<br>Controls blood pressure; Heart medicine     |                | 1 Capsule |            |           |                              |
| <b>Prilosec<sup>®</sup></b><br>(Omeprazole)<br>20 mg Capsule(s)<br>Treats/prevents stomach ulcer/heartburn |                | 1 Capsule |            | 1 Capsule | 1 Capsule                    |
| <b>Coumadin<sup>®</sup></b><br>(Warfarin)<br>1 mg Tablet(s)<br>Thins blood                                 |                |           | 1/2 Tablet |           | 1/2 Tablet                   |
| <b>Aspirin</b><br>81 mg Tablet(s)<br>Prevents blood clots                                                  |                | 1 Tablet  |            |           |                              |
| <b>Januvia<sup>®</sup></b><br>(Sitagliptin)<br>50 mg Tablet(s)<br>Lowers blood sugar                       |                | 1 Tablet  |            |           |                              |
| <b>Zyrtec<sup>®</sup></b><br>(Cetirizine)<br>5 mg Tablet(s)<br>Relieves symptoms of allergies              |                |           |            |           |                              |
| <b>Boniva<sup>®</sup></b><br>(ibandronate Sodium)<br>150 mg Tablet(s)<br>Prevents and treats osteoporosis  |                |           |            |           | Take one tablet<br>per month |

The pharmacist may make a generic substitution for the medication shown on your daily schedule. Please check dosage strength on your daily schedule. Call your pharmacist if you receive medication that is different from what is shown on your medication schedule.

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## Want a Discount on Generic Medications?

Price your meds with one or more of these sources:

[BlinkHealth.com](http://BlinkHealth.com)

[GoodRx.com](http://GoodRx.com)

[NeedyMeds Drug discount card](#)

I have used BlinkHealth and it has saved money on most of my generic medications. BlinkHealth has partnered with specific pharmacies. For example, for my brand name prescriptions, I still use my insurance at CVS, but for generic meds and using the BlinkHealth discount, I get those at Gwinnett Drugs. You can also have your medications mailed to your home for an even greater savings. —Cheryle



*Pixies's Perspective*

*Support Group Meeting –July 27, 2019*

July Georgia Support Group Meeting  
July 27, 2019

Tom Cox, A Story of Myositis

Tom Cox and his wife Evelyn are frequent attendees at our meetings. Tom is generous with praise and encouragement for everyone. He has maintained a positive, but realistic, outlook through his 12 year journey with IBM. He agreed to share some of his hard earned wisdom with us.

Tom's goal with this informal talk, was the hope that all patients and caregivers might find something to relate to from his experience.

His story began with falling and weakness, familiar to most of us. Then on to a neurologist who seemed to have no clue about what to do - also familiar to many. Next, a trip to the VA where a young doctor immediately suggested a possible diagnosis of IBM, only because he remembered hearing something about it in medical school. Tom felt lucky to get an answer - until he googled it! Tom accepted that he had the illness but admits now that he thought, 'I will be the lucky one who won't advance too far'.

Tom did more research and discovered TMA. He and Evelyn went to the conference in Louisville, Kentucky thinking that Evelyn would just enjoy a pleasant day in town. When Tom saw the men in wheelchairs and reality hit hard. He called Evelyn, asked her to join him, and their education started. Constant research about IBM is important for coping with his IBM.

There are some common experiences we share on our journeys. Confusion and questions - why does one treatment work for that person and not me, why is that person's progress so different from mine, does everyone feel alone like me, how can I find the right doctor, what started all this, how can I avoid another set back? There are no easy answers to these concerns but Tom's presentation encouraged us with good practical advice such as:

Acceptance is not surrender or limiting - it confers power for coping with this reality, for getting the help you need.

Find fun activities to enjoy. Exercise is essential but too much can also harm muscles.

Tom and another IBM'er, Augie D'Augustinis, both used E-stim devices after consulting with Dr Stephanie Palma in Dahlonoga, GA. (Check the newsletter from the July 28, 2018 Support Group Meeting).

Avoid stress. Tom gave up arguing with ornery people on Facebook!

Expect setbacks.

Find a doctor you are comfortable with. One who listens and consults with others when needed and will do extra research for answers to your questions.

Know your disease. Use the TMA online support section. Tom found a doctor he respects at the Johns Hopkins Myositis Clinic.

Get professional mental health support if needed, and for your caregiver as well.

Become your own advocate or designate a caregiver to help.

I will mention here a final note of wisdom, a personal aid to mental health perhaps, that Tom told us he often used to ask his daughter at the end of the day:

"What did you do today that you are proud of and what are you looking forward to tomorrow?"

I hope we all find personally satisfying answers to those questions each day.

....Pixie



Support Group Newsletter

Cheryle Miller  
301 Cannon Farm Road, SW  
Oxford, GA 30054

Cheryle 678.386.2435  
Pixie 832.262.8646  
CheryleMiller@comcast.net



THE MYOSITIS ASSOCIATION

[www.myositis.org](http://www.myositis.org)



If not yet a member,  
Please join TMA!



*Our Support Group is  
celebrating 10 Years!!*

*Please join us at our next  
meeting on November 9th to  
celebrate...:*

*PS... there'll be cake!!*

