



# Myositis Newsletter



THE MYOSITIS ASSOCIATION

## Georgia Myositis Support Group Newsletter

Volume 19, Issue 1

*~Next Meeting~*

**May 18, 2019**

**Gwinnett Library, Collins Hill**

455 Camp Perrin Road, NE

Lawrenceville, GA 30043

10:30pm-2:00pm

**Lunch included, reservations are a must!**

Have questions? Call 678.386.2435

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

Reservation forms will be emailed on May 10th.

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Our special guest  
**Mary McGowan**  
**Executive Director**  
**The Myositis Association**

Plan to attend our next meeting on Saturday, May 18th, and have an opportunity to meet TMA's new Executive Director. Mary will give us an update of TMA news and answer questions that you may have about research, trials, medical advisory board and information on this years conference.

*Welcome to Georgia, Mary!*

**Our  
Next  
Meeting  
is planned for  
August  
Date TBA**

**2019  
Is Our  
Support Group's  
10 year  
Anniversary**

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## Converted Van and Power Wheelchair for Sale

One of our members, Jim Dooley, is selling his van and power chair. The van is a 2015 Chrysler Town and Country. Champagne in color. It has many features including a side door power ramp. The Quick lock bracket has been installed on passenger side. Also included are portable Q strains to transport another chair. It has a Leather interior, DVD player, XM radio and CD player with MP3. You can see pictures of the van on AMS Vans classified website. Jim is asking \$28,500.

The wheelchair has hardly been used. It's a Permobil M3 Corpus. It has all the bells and whistles including a lift, fully reclines and it also has 2 joysticks. One is mounted on the armrest and the 2nd on the back of the chair for the caregivers use. He would like to get \$3500.00 for it. He is including a 6 foot portable aluminum ramp at no additional cost.

You can reach Jim at 706-831-3449.

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## Annual Patient Conference ~ Minneapolis, Minnesota September 5-8, 2019

### Doubletree by Hilton Bloomington-Minneapolis South

7800 Normandale Blvd, Minneapolis MN 55439

Rate is \$112 a room per night, use Group code TMA9 to book, phone 952.835.7800

Conference registration fee is \$225 per person. Call TMA at 800.821.7356

More conference details are online at [Myositis.org](http://Myositis.org)

If you have never been before, it is so worth the trip. The sessions are very valuable, as you learn so much from myositis experts and get to meet many people with your form of myositis.





## Products That Benefit

### Carex Uplift Premium Seat Assist

\$119.15 on Amazon.com Free shipping with Prime

Seat lifts are lifting devices that are designed to help you stand from a seated position.

This model is for use on a car seat, sofa or regular chair. It has 70% lifting ability for up to 230 pounds. Seat lifts assists are also available for recliners. They are made a bit differently, so if that is what you need, make sure that it works with a recliner.

I encourage you to read the customer reviews to see which model might be appropriate for you.



## Soleo Health

A big **Thank You** to Jessica, Jennifer and Hews from Soleo Health.

*They are providing lunch to our group for our May Meeting!*

Soleo Health is a specialty infusion service that provides IVIG infusions administered by a nurse, in the comfort of your own home.

Feel free to ask them at the meeting about any questions you might have about IVIG, home infusion and insurance coverage. If you cannot attend the meeting, call 470-226-2300.



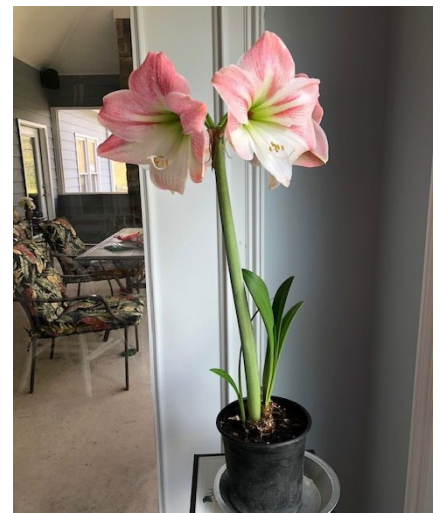


### A note from Cheryle ~One Nice Thing a Day

I read a blog called **Rhonda's Creative Life**. It's written by Rhonda Buss, whom I really have come to admire. I found her blog as I looked at sewing blogs a few years ago and enjoy seeing the lovely articles of clothing that she makes. Rhonda is so much more than a seamstress, she is also a wife, a pilot, a 'soup cooker' and a doggie Mom. She shares her knowledge of so many things on her blog continues to inspire me on so many levels. Recently, she broke her wrist and that has caused nerve damage to her thumb and pointer finger. She told her therapist that she likes to knit and now knitting is some of her therapy. She continues to make lemonade from lemons that life throws her way.

Rhonda is currently sharing her ideas of Doing One Nice Thing a Day for yourself. Again she has inspired me. I've been growing an Amaryllis bulb left from Christmas 2017. When the stem started shooting up, every morning I would text a photo to my granddaughter, Celeste. She was as fascinated as I was! It bloomed this week and is simply gorgeous. It's wonderful to share something delightful across different generations.

So many times we get wrapped up in our Daily 'TO DO' List, that's chock full with Doctor appointments, therapy appointments and trying to get a handle on our insurance, that we hardly have time to think of doing a nice thing for ourselves. I take a few minutes to read a book from the library, listen to 60's & 70's music and I'm taking online classes. These little things really enhance my day. I hope you can find a nice thing for yourself each day.



Look at page 7 to see what Nice Thing I Did for myself today.



*Pixies's Perspective*

*Support Group Meeting -February 9, 2019*

*Emory Rheumatologists Dr. Prateek Gandiga and Dr. Suzana John*

Dr. Gandiga and Dr. John were with us for almost 2 ½ hours! It was like having our own Mini-Myositis Conference. We got good news, medical and research explanations and interactive dialogue which included questions and suggestions from our members.

The doctors' goal was to tell us they have been exploring the possibility of creating a multidisciplinary clinic at Emory, a comprehensive center, for research and the treatment of systemic autoimmune diseases - prioritizing Myositis conditions. Good news! They would like Emory to be a 'resource for patients, caregivers and other physicians in the community'. Doctors from many disciplines (pulmonology, dermatology, immunology, physical therapy, cardiology, pathology and sociology for example) have expressed interest in this collaboration. The best news is that their 'boss', the head of the Immunology Dept, is enthusiastic about the concept.

They have consulted doctors in other parts of the country, for example, Johns Hopkins Myositis Center, who have created such centers. Dr. Gandiga and Dr. John were clear that to build a solid and successful operation, steps need to be taken in an orderly and deliberate manner. This will take much planning and lots of time, but other centers may share good advice and experience to make the process more productive. Our area is more spread out and has a lower population density than the coastal cities, however, making the goal harder to reach. They are asking patients like us to explain our previous experiences and to describe our ideal concepts for clinical care.

Our challenge is to help Emory create a clinic:

First, please ask your doctors - anyone who treats you - to get in touch with Dr. Gandiga or Dr. John in the Rheumatology Dept at Emory. They need to create a database of physicians for networking and collaboration. They need to let every doctor we can find, know that even before a clinic exists that Emory can be a resource for second opinions and consultations. In the future there will be opportunities for local conferences/training/research but they need a critical mass of interested professionals, from multiple disciplines, to accomplish this goal.

Second. We need help finding out how many patients there are in our wide area (within multi-state travel distance). Cheryle only gets the names of people who have joined TMA (no dues or membership fees remember - and donating does not automatically put you on the list. Please fill out the online membership form) We don't need names, if your doctor can just mention how many myositis patients they treat or know of. The other Myositis online forums you may chat on could use this information/request about Emory's goals too.

Some of the most important goals of present research are: 1. Determining protocols and training for taking biopsies and reading the slides, 2. Finding new markers for different types of myositis conditions, 3. Creating blood tests to find specific antibodies and muscle enzyme markers, 4. Studies of the entire immune system in the context of auto immunities. Each patient's complex of symptoms and needs is different. Drs. Gandiga and John emphasized that researchers must look at all parts of the immune system, to see which has gotten out of balance and is attacking healthy tissues. We should no longer confine treatments to set 'families' like DM and PM and IBM but to specific individuals who are experiencing one of many 'systemic autoimmune diseases' and the multiple ways it affects the body.

Pixies Perspective, continued

A few comments of interest the doctors shared at the meeting: Studies in Sweden have shown that exercise, at whatever level you can manage, did not cause harm and can help, especially with resistance activity included.; Medications are only half of the treatment - support and lifestyle adjustments can help with good outcomes.

More good news!

Mary McGowan, our new Executive Director of TMA, is very excited about Emory’s concept. She can be an advocate for Emory’s involvement in research and suggest funding opportunities and requirements. She has already emphasized that we need a large pool of patient participants in order to entice organizations and companies’ research grants. They need good data and a network of doctors before any of the fast disappearing dollars can be accessed. Even once funding is found, trials for treatments can easily take 3-5 years or longer. Mary is attending our next support group meeting May 18th. Do plan to come if you can, to meet her and hear her speak about TMA and her plans to make it even better.

Finally, Dr Gandiga told us that the incidence of myositis in the population is 0.0001% and of IBM is 0.0003%. We indeed have a rare condition. The experience that we shared, those of us who had a good enough day to physically manage to get out of the house for this meeting, the information we are sharing through this newsletter and the TMA website for those who had to rest at home, is heartwarming and hopeful.

Best wishes to all of us!

Pixie

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**A thank you note from Dr Gandiga after the Feb 9th meeting**

Thank you again for allowing us to meet with your group this past Saturday. It was a pleasure to meet all of your members and learn more about their stories and the great work that the chapter has made in their ongoing myositis care. Thank you all for the wonderful feedback about barriers and benefits that would be helpful to patients: it’s been invaluable for helping us strategize areas to focus on next.

We’ve gotten the chance to speak with our division chair and colleagues in other divisions. Everyone is still strongly behind the effort to tangibly strengthen the multidisciplinary myositis clinical care setup at Emory and use this to help build research opportunities and a better clinical trials program here. We’ll definitely continue to let you and the members know as we progress. We are also using your feedback to help us build better educational opportunities for other medical providers both at Emory and in the area.

Please let us know about any upcoming events that you might have as well, as any ways in which we can work with all of you to be a good resource for you and your members.

Looking forward to seeing all of you soon, but until then

Best!

Prateek (Gandiga) and Suzana (John)



**Support Group Newsletter**

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**THE MYOSITIS ASSOCIATION**

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



*Do  
One  
Nice  
Thing  
a Day  
For Yourself!*



**I've ordered a new Amaryllis!**

They're so easy to grow... just a little water and bright light.

I hope I've inspired you to be nice to yourself today!

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