



Myositis Newsletter



THE MYOSITIS ASSOCIATION

Georgia Myositis Support Group Newsletter

Volume 17, Issue 2
Autumn 2017

~Next Meeting~

November 4, 2017

10:30am-2:00pm

Collins Hill Library

455 Camp Perrin Road, NE

Lawrenceville, GA 30043

Reservations are a must!

Please call Cheryle 678-386-2435

or email CheryleMiller@comcast.net

Before October 30th.

2018
Meeting
Dates
To Be
Announced

New Members

New members

attending in August

Roland & Pat Lallier

Dale McCall & son Brian

Welcome!

Ronnie Genser

**President of
Bereavement Navigators**

Speaking on

**“Making Advance Care
Planning Easier with a
POLST”**

Why everyone needs to implement this relatively new medical document in addition to having a Georgia Advance Directive for Healthcare



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MYOSITIS AWARENESS MONTH

“What’s That Thing You Have Again?”

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Most of you will remember the **Myositis Awareness Information Sheets** for each form of myositis, that I wrote in the spring for our Myositis Awareness Project. These include information on your specific disease, and were for you to use to hand out or mail, to family, friends etc.

We had a great response from members passing out these letters. Many said it was exactly what they needed to help their family understand their illness!, If you would like more copies to share with friends or colleagues, I am happy to send them to you. I also plan to include a copy in the new member welcome packets.

Cheryle

Products That Benefit—Members Suggestions

On the next page I am highlighting two products as usual, but these were recommended by one of our IBM members, Bob Wildrick. I believe that sharing our experience is the best way to find products that are truly helpful to our members and very importantly, worth the cost. Please contact me with suggestions for products for our next newsletter

I am also happy to share information on products that you’ve had a negative experience with. This information, both good and bad, will be useful not only to the members who attend our meetings, but also the members who are unable to attend our meetings

Thanks in advance for sharing!





Products That Benefit

Lift Seat 4 Home

This lift can be used over the commode, or with accessories, at bedside. It is recommended by Bob Wildrick one of our members who has one. His number is (706)745-0974.

This company supports TMA and if you mention TMA when you purchase one, you will receive a \$100 discount.

To see a video of how it works, check out their website:

www.liftseat4home.com

For more info: (877)665-4381



Golden Tech Lift Recliner

Also recommended by Bob Wildrick, (706)745-0974. He said this brand lifts on both vertical & horizontal and is a better chair for those with IBM.

He suggested not to buy over the internet as it is sent as freight and left at your door. Instead, buy from a dealer, who will deliver and set it up in your home. There are several locations in Georgia.

Tucker location 770.939.7160

www.GoldenTech.com





Useful Information ~ Free Phone Apps

WheelMate is an app that helps users around the world locate wheelchair-assessable toilets and parking spaces. Locations are added and verified by fellow wheelchair users to ensure the information stays up-to-date and useful.

Free, iOS and Android;

www.wheelmate.com



AXS Map is another people powered app that is kept up to date by users. It works with Google Maps to allow people with disabilities to find accessible restaurants, hotels and stores, among other places. Users rate and review the locations.

Free. iOS and Android

www.axsmap.com

If you are not yet a member of TMA, please join

The Myositis Association

www.myositis.org 800.821.7356

We would like 100% of our group to be a part of TMA,
so that you have access to all that they offer,
and to support them, as they support our group



Pixies's Perspective

August 26th, 2017
Myositis KIT Group

Lisa Mise
Coordinator for Behavioral Health Services at
Northside Hospitals
Behavioral Health Helps People Heal Faster

Northside is the first group of hospitals in Atlanta to offer this onsite service. Lisa guides the program at all three of its hospital locations. Lisa and her teams are a compassionate and encouraging resource for patients with chronic illnesses. The Behavioral Health unit works in conjunction with medical services and concentrates on 'illuminating the complexities of adjusting to illness'. They work with patients who are newly diagnosed and also those who already have a chronic illness.

The Behavioral Health service provides:
Emotional support for patients and caregivers
Education about coping with long term illness
Strategies for living with chronic illness

Lisa suggests that adjusting long term illnesses is similar to a grief process. There are common patterns and topics, for example - sad feelings, self pity, grief, fear, denial, anxiety. It differs by patient and circumstances and the topics can repeat through time.

There is however, power that can be learned by dealing with your disease and treatments. Acknowledging and validating feelings as they arise instead of shifting into denial and avoidance helps patients learn coping strategies. Being prepared helps people learn resilience and leads to greater self-respect. Remind yourself of your humanity. Illness happens and it is no one's 'fault'. It is not lack of character which triggered this. There is no guilt or shame with having an illness. You did not do anything 'wrong' to cause this autoimmune disease. Don't think 'I brought this on myself' or 'I did not eat right' or 'I did not do the right things in life'. Pass through the 'why me' phase as quickly as you can. You can become more compassionate (with other suffers in the world and with yourself). You will become a more resourceful person.

Lisa gives important advice for patients and the people who love them

- Honor your limitations
- Let go of expectations
- Validate your feelings and express your fears and needs
- Every day you are sharing these experiences with others who are in pain or distress
- Experience your grief - it is real and the only way to get to the other side, is to go through it, not avoid it

Continued on next page





Pixie's Perspective, continued

- Beware of negative and scary information online. Limit yourself to avoid becoming overwhelmed.
- Expect to feel powerless at times
- No one is perfect
- Evaluate the impact of what you do and think, and the decisions you make for yourself and others. Evaluate their positive and negative impact
- Recognize the challenges you have overcome and the lessons you have learned. This is one of the most important tools you have for learning self respect, resilience and compassion for your own experience
- Tell yourself "I can learn from this"
- Learn to listen to your own body
- You will not have the same experience as anyone else. You are unique!
- Your experience will change through the course of the disease.
- Courage doesn't always roar - little steps can often take as much bravery as large ones
- One of Lisa's favorite quotes is "Life is learning how to dance in the rain"

This is a book she recommends - '**How To Be Sick**' by Toni Bernhard

I think everyone who attended the KIT meeting could feel Lisa's empathy and interest in our conditions. She showed compassion for our experiences. She learned from us as well and we can recognize how our sharing will help others through her work.



Do you shop online at Smile.Amazon.com?

When you sign up for www.Smile.Amazon.com, choose Myositis Association of America as your choice of charity, and with each purchase, Amazon will make a donation to TMA to help fight Myositis.

What an easy way to help make a difference!





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



MAY IS



MYOSITIS AWARENESS
MONTH



Keep In Touch

TMA uses the acronym KIT (Keep IN Touch) to refer to the support groups. Due to confusion of several members when our group was started, we have never used the term KIT, but rather focused on the word "Support."

I have encouraged members to 'keep in touch' between meetings since our meetings are only 4 times a year. I hope more members will buddy up and contact each other throughout the year by exchanging phone numbers and email addresses.

If you would be willing to provide a ride to someone who lives close by, please let me know. ~Cheryle

