



# Myositis Newsletter

THE MYOSITIS ASSOCIATION

## Georgia & Alabama Support Group Newsletter

*Our next meeting*

### November 14th

665 Duluth Highway (120)

Lawrenceville GA 30046

*Two Speaker Presentations!*

### Mike Bloomfield

Pharmacist at

### Emory University Hospital

Mike works with and dispenses many of the medications we take, e.g., IVIg, Rituxan, Cytoxan, Cellcept

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### Chad Chambers,

Healthcare Service Coordinator

### Muscular Dystrophy Association

Chad will inform us what MDA services are available to us, since Myositis is under the MDA umbrella of muscle disease.

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*Confirmation & lunch order form to be sent by email early in November.*

Family and friends welcome to attend.

#### Meeting Dates

2016

January 23rd

April TBA

July TBA

October TBA

Volume 15, Issue 3

Autumn

2015

### *New Members*

We had 5 new members attend in August

Sharon Moorman, PM

Mary Smiley, PM

Kimberly Tucker, PM

Stella Clapp, IBM

John Carel, IBM

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We've been invited to:

## MDA Family Day and Fall Fest

*Free, Free, Free!*

Sunday November 1st , 2pm –5pm

### Blackburn Park

3493 Ashford Dunwoody Rd, NE

Atlanta, GA 30319

Costume contest ~ Tricks and Treats

Pumpkin Design Competition ~ Entertainment and Games

Face Painting ~ Info on Clinical Trials

To register for Family Tickets 770.621.9800 or

Email ~ [echavez@mداusa.org](mailto:echavez@mداusa.org)

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### Polymyositis or Limb-girdle muscular dystrophy (LGMD)?

Muscular dystrophy can mimic inflammatory myopathies like polymyositis. A type of limb-girdle muscular dystrophy, LGMD2B, is especially prone to misdiagnosis as PM. It is very important to pursue a correct diagnosis to avoid the side effects of ineffective treatment which can include non-recoverable loss of strength.

### No-Cost LGMD Genetic Testing

**MDA clinics to offer testing for those with weakness in proximal muscles who do not have a confirmed genetic diagnosis**

Limb-girdle muscular dystrophy (LGMD) is a disorder with more than 30 genetic subtypes that results in a weakness of the muscles surrounding the shoulders and hips. These are also sometimes referred to as “proximal” muscles because they are located near the center of the body.

In the past, supportive treatments for LGMD did not differ based on subtype. More recently, clinicians have worked to consider the subtype of LGMD in monitoring and treating people because some subtypes are more likely than others to involve cardiac or respiratory muscles. In some cases, weakness of the proximal muscles is associated with a metabolic muscle disorder known as Pompe disease (acid maltase deficiency), for which disease-altering enzyme replacement therapy is available. Proper diagnosis can help people access appropriate care faster.

With support from Genzyme, a Sanofi company, and in collaboration with Emory University, **MDA clinics are now offering testing for people who have weakness in proximal muscles and who do not have a confirmed genetic diagnosis.** Based on testing of a saliva sample collected at an MDA clinic and sent to the Emory Genetics Laboratory, the results are returned to physicians and communicated to participants within two to three months.

For more information about testing related to weakness in proximal muscles, please speak with your MDA health care service coordinator or clinic physician. To learn more about LGMD and its many forms, read In Focus: Limb-Girdle Muscular Dystrophy, which includes a helpful Q&A with genetic counselor Christina Trout.





**Renee Capriola**  
will be honoring her mother  
in a  
**50K Walk**  
for  
**Myositis Awareness**  
December 19 & 20  
Atlanta



I am turning 50 in December and want to do something significant to mark this milestone... since you only turn 50 once! I came up with this (hopefully not too crazy) idea to walk a 50K over 2 days (12/19 and 12/20) and raise money to honor my mother, Helaine, who was diagnosed with a rare and debilitating, muscular disorder called (Inclusive-Body) Myositis about 15 years ago...for which there is still no cure. Her condition has worsened, but she is very strong, stubborn, and determined to not let it beat her!

I would love for you to support me in my efforts to walk a 50K and raise money for this very, worthy cause by donating \$50 or more to my fundraiser "**My 50K to fight Myositis.**" Additionally, if you will be in Atlanta during this time, please join me for part of my walk (I will send out my routes in future emails) and/or celebrate with me at the end of my 50K on 12/20 (more info to follow).

Donating is really easy to do! You can either send me a personal check for the donation or go on to my fundraising page that I created thru the Myositis Foundation (see below). All of the money that I raise will go toward research, treatment, and hopefully finding a cure one day for Myositis. Additionally, the fundraising page provides a lot of links to information explaining this not-so-well-known disease.

<https://myositis.secure.nonprofitsoapbox.com/50k-to-fight-myositis/50k-to-fight-myositis>

Thank you in advance for your support...it means the world to me and to my mom!

Renee Capriola  
1242 N Highland Ave NE  
Atlanta, GA 30306  
678-860-8597





## Alabama, Welcome to our 'Myositis Family'!

Since there's no active Support Group in Alabama, we would like you to be a part of our group. If you are able to attend our support group meetings, we would love to have you.

For those who are too ill or who live too far away to attend the meetings, I hope you will find this newsletter to be helpful and informative. Please remember, we are just a phone call or email away.

**CheryleMiller@comcast.net** or **678.386.2534**

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### Doctors Business Cards

We have started keeping a database of rheumatologists, neurologists and physical therapists. 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 next meeting, or email the information to Cheryle.

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### Useful Websites

Many helpful products are available through these websites:

**WrightStuff.biz**  
**Mobility-Aids.com**  
**CareGiverProducts.com**  
**ArthritisSupplies.com**  
**ActivenAble.com**  
**GoldViolin.com**

### Products that Benefits

#### Key Turner

Heavy plastic handle that provides extra leverage for easy turning. Holds 3 keys.

\$9.95 WrightStuff.biz





### ‘Pixie’s Perspective’

Dr Chester Oddis is a member of the TMA Medical Board. He practices, teaches and researches medications at the Pittsburgh Medical Center, PA. He is a master at making medical information clear, organized and understandable for patients. I will try to follow his lead with this synopsis,

#### How do Physicians Choose DM and PM Medications for a Particular Patient

There were two main messages: 1. The Doctor chooses the most effective drug or drugs which fit the patient’s symptoms “according to the data that looks best in terms of the responses that we get” with the disease progress. 2. A decision is made through a process that is part Science, Art, Comfort and Data

**Science** These drugs generally decrease the inflammatory response that is attacking the patient’s body. Many of these drugs have been borrowed from cancer treatments and transplant surgery treatments used to modulate rejection of the new organ. The doctor needs to consider side effects, overlap illnesses, blood tests and target symptoms (like skin, joint, lung problems) There are around 6 categories of drugs for these uses:

1. Steroids - quick and cheap and can be effective a different dosages
2. Immunosuppressants like methotrexate and Imuran (azathioprine) - using a different method of action, different dosages can be used or different methods of administration can be tried before giving up on any of these
3. Combinations of drugs
4. Things like Cyclosporine and Tacrolimus (especially useful for ILD patients) - which target different mechanisms of inflammation
5. Non-immunosuppressants - IVIG which help modulate the immune system and work well for skin problems, swallowing problems, and lung problems
6. Biologics - including Rituximab, Enbrel, Humira (adalimumab) which have been borrowed from cancer and Rheumatoid Arthritis treatments

New experiments - for instance a new trial for an anti-interferon marker found mostly in DM patients

**Art** Try for a good match for a patient’s reported symptoms, preferences and continuing feedback.

**Comfort** A physician’s confidence with a particular medication, their personal experiences and trial and error with controlling the patient’s symptoms and side effects

**Data** This is the most complex because Rituximab is one of the only drugs which has had a scientifically controlled study done specifically for Myositis. Importantly, other drugs formerly used to treat other diseases also have had few controlled studies, and mainly rely on a history of success. Case studies and retrospective studies do not have solid data so for each individual there is trial and error elements for success.

So - the decision process uses about five different elements.

1. First try the most studied drug with a history of success plus analysis of blood levels for multiple known factors
2. Match the drug to the patient’s target problems (lung, skin etc.) and side effects
3. Try combinations of drugs according to knowledge of studies, the doctors personal experience and blood tests
4. Use a continuous/dynamic approach - change medications or increase/decrease dosages of present drugs or change the intervals of use

Add holistic elements - sleep, exercise, healthy diet. Try adding turmeric, fish oil, and, for hair loss try adding folic acid and biotin

This final message from Dr Oddis -

***Know your body and keep talking to your doctors!***







August Support Group Meeting 1st Presentation

FODAC - Friends of Disabled Adults and Children  
4900 Lewis Rd, Stone Mountain, GA 30083  
770.491.9014

*Keeping People with Disabilities Moving*

FODAC has been in business for 20 years, serving approximately 5000 clients a year in many US states and other countries. They have 20 staff members and volunteers are welcome. There are 30 collection centers throughout GA and SC for used medical equipment.

Their primary location includes the Office, Warehouse and Thrift Store. The Office is open Monday thru Friday, 9:30-12 and 1-4:30. Please call Betty Felder for an appointment at 770-491-9014 (first come first served). The Thrift Store is also open on Saturday 10-4

Ms. Donyetta Green showed a charming video which illustrated their services:

1. Recycled medical equipment
2. Modify homes, modify vehicles
3. Helps to decrease worry in permanently or temporarily disabled clients by offering items at low or no costs
4. Travel for national disaster relief activities
5. Assists caregivers - for example - to build temporary or permanent wheelchair ramps
6. Recycles and repairs technology for non-verbal communications
7. Provides independence aids for daily living
8. Creates empowerment to enable access to jobs, school and family life

Their operational support funding comes from

1. 25% from the government
2. 20% from the Thrift Store profits
3. 7% from Corporations
4. 12% from individual donations
5. 20% from fundraisers
6. 16% from other individuals

For every \$1 provided, they can provide \$10 worth of equipment free to clients. They work with contractors for household and vehicle renovations. They have relationships with many hospitals. They can help find grants to fund projects. For repairs to medical equipment, there is a one time fee of \$25 for as much as you bring to that one session - though you may have to pay for tires or other parts. Everything which is reused is sanitized, modified or repaired and reissued at little or no cost to clients.

They do not deal with any insurance. Almost everything is paid for by grants and fundraising. They hold 3 fundraisers each year - one at Stone Mountain Park, a Golf Tournament and a very popular Santa Breakfast in December. It is heartwarming to know that there are people in the world who bring good news, help others in need and say they feel privileged to do this work.

August Support Group Meeting, 2nd Presentation  
*Soleo Health ~IVIG Infusions ~Jessica Frye 470.345.9288*

The program began with a presentation by Kathy Eubanks, a home infusion nurse, and Jessica Frye, a community liaison nurse from Soleo Health in Atlanta. Jessica first asked attendees to fill out a short survey about support groups - why you attend, how it helps and how Myositis affects your life.





Soleo Health IVIG Infusions continued....

Her purpose is first to learn more about the disease process and second to have patient input so that she can create a flyer to give to Doctors she works with. She has found that few of them know that support groups are available. (Some people mentioned online support, TMA online and Facebook groups as well)

Comments from members mentioned benefits including: encouragement, support, information, comparing symptoms, hope, purpose, friendships around the world as well as home, not feeling alone and learning about adaptation devices for IBM patients. Statements from caregivers prompted Jessica to stress that "caregivers are living the disease along with you".

Kathy and Jessica then presented information about IVIG treatments. It is used for many diseases but for Myositis it is used primarily for PM and DM. It is a human blood product containing helpful antibodies that patients may be missing. It is pre-screened for hepatitis and HIV before manufacture. The dose is based on the weight of the patient. It can be effective with different timing between doses and can be used, if needed, for long periods of time. It is often given along with other familiar medications. Timing and dosage as well as speed of the infusion or brand of IVIG can be changed at any time as needed to control side effects or new Myositis symptoms.

IVIG works by modulating (but not completely suppressing) the overactive immune response which is attacking the patient's own system. It gives energy and can help fight off secondary infections.

There are different brands and each has a slightly different formula - for instance, some contain sugar and others are sugar free used for cases of diabetic or kidney patients. Your Doctor will suggest a brand based on your medical background and symptoms, any previous side effects or allergies, your insurance coverage and nurse input.

Finally, Jessica said that some infusion nurses or facilities use a few pretreatments to prevent side effects like headache or slight nausea. The options include: Tylenol, Benadryl and, most important, Hydration. She suggests hydrating the day before infusion (or even for the entire 7 days before), hydrating the day of and the day after the infusion.

There was a good amount of participation by the patients and caregivers attending the KIT meeting. Suggestions, questions and comments were graciously answered by both nurses. It felt like this presentation fulfilled a need for clear and useful information about this helpful and common treatment.

I want to especially thank Cheryle for the hard work it takes to find and schedule these presenters for our group. We learn so much!

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**Life As An Anomaly, 21 Things you need to know**

With permission, by B.R., who is battling multiple chronic diseases

1. Be positive, I say it so often that it is number one on my list. You have a chronic disease, and you feel like crap physically. Why take yourself there mentally too? When you start to look at everything in a positive light, life in general is a pleasure, despite how crappy you feel physically.
2. Love yourself for who you are. You are a different person. Accept it. Embrace it.
3. Allow yourself to feel emotions. Be angry, be sad, be everything that you feel. But feel it, acknowledge it and let it go.
4. Always question your doctor about everything. They want you to take a new medicine, ask what it is for, what it does, and what are all the side effects. He she has to tell you if you ask.

To be continued next newsletter... To read them all now go to: [lifeasanomaly.com](http://lifeasanomaly.com)



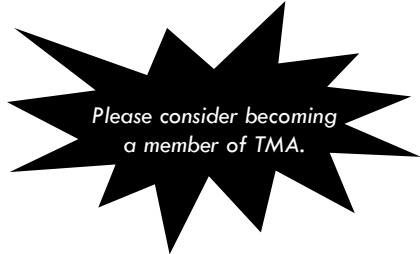
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THE MYOSITIS ASSOCIATION

www.myositis.org



Please consider becoming  
a member of TMA.



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In Memory of  
**Shaundra Barkley**  
Age 42  
Forsyth, Georgia  
We have lost another member to Polymyositis  
with Interstitial Lung disease.  
May Shaundra Rest In Peace.

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### Myositis Awareness Month, May 2016

*Picnic in the Park*

In 2016 The Myositis Association will begin celebrating **Myositis Awareness Month** rather than just one day. We voted to hold a picnic and are forming a committee to pull it all together. We have a few volunteers, but need a few more, so that it isn't too big of an project for any one person.

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

### 2015 Conference Orlando



Cheryle Miller representing Georgia at the conference.

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