



# Myositis Newsletter



THE MYOSITIS ASSOCIATION

## Georgia Myositis Support Group Newsletter

Volume 18, Issue 3

*~Next Meeting~*

**November 10th, 2018**

Please note: **DIFFERENT LOCATION!!!!**

Gwinnett Library, Collins Hill Branch

455 Camp Perrin Road, NE

Lawrenceville, GA 30043

10:30am-2:00 pm

**Reservations are a must!**

Have questions? Call 678.386.2435

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

Reservations /Lunch form will be emailed by Oct 30th

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### *Our Agenda*

10:30 am **'Meet and Greet'** over Coffee

11:00 am speaker **Scott Morrison** of **BrightStar Care**

12:00 pm **Lunch**

12:45-pm-2:00pm **Breakout Sessions**



|                 |
|-----------------|
| <b>2019</b>     |
| <b>Meetings</b> |
| <b>January</b>  |
| <b>April</b>    |
| <b>July</b>     |
| <b>October</b>  |

### New Members

Attending

In July

Gary & Carolyn Madson

Cheryl Eppsteiner

Karen Perkul

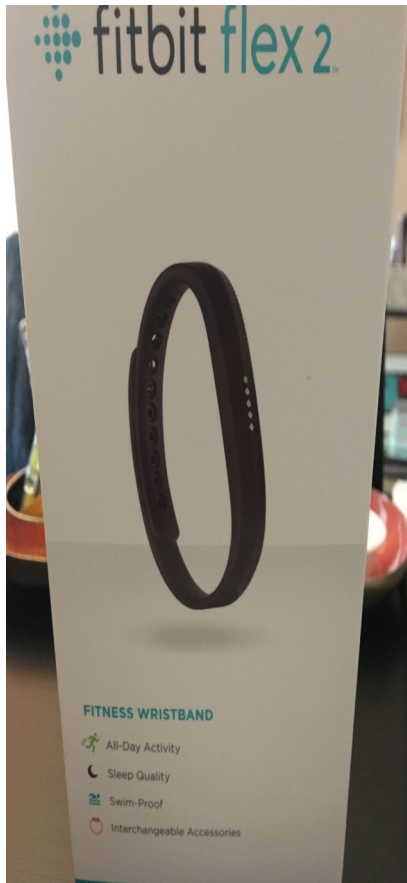
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Welcome, y'all!

### Inside this issue:

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### *Support Group Fund Raiser*

It's not often that we hold a raffle, but buying a raffle ticket is an easy way to support our group now that we must pay for our meeting room. Buy a ticket and take a chance at winning a very nice prize:

### **A fitbit flex 2**

**Donated by Gail Edwards**

We are not allowed to collect money for a raffle at the library, so if you would like to purchase a ticket or two, you may add that chosen amount to the total on your lunch & meeting reservation form, so that I receive it in advance of the meeting.

If you are unable to attend the meeting Nov 10th, but would still like to buy a ticket or two, you can mail a check to:

Cheryle Miller

301 Cannon Farm Road SW

Oxford GA 3005

**1 ticket for \$3**

**2 tickets for \$5**

**5 tickets for \$10**

Drawing on December 1st

PS Would make a nice Christmas gift!





## Products That Benefit

### Zippo Rechargeable Hand Warmers

For those of us with poor circulation, Zippo makes rechargeable hand warmers that don't require fuel. They are powered by a lithium-ion battery that can be charged into any outlet or computer. Prices vary as to model size and to how long the charge is good for, either 2 hours or 6 hours. They can also be used to recharge your phone. Prices vary greatly. Shop around!

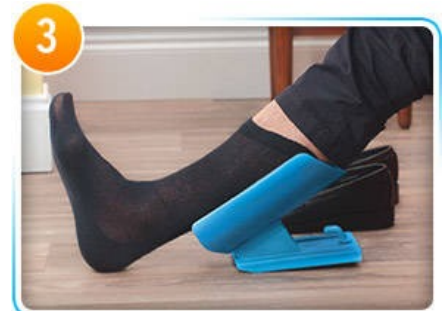
At the time of writing this newsletter, Amazon had the 6 hour model for about \$24 (Zippo had it for \$45)



### Sock Slider

Assistive device to aid in putting on socks and shoes.

Allstar Innovations Sock Slider -An easy on, easy off sock aid kit and shoe horn. \$12.46 at Amazon.com





## Helpful Apps

**Medical Dictionary** by Farlex. A free app that searches more than a dozen authoritative sources for medical terms and is a source for definitions and information on anatomy, physiology, diseases, drugs, treatments, tests and procedures, medical research topics and much more.

**Howjsay.com** This app helps you learn to pronounce your medications and medical terms correctly. \$2.99

**WebMD** A free app that offers healthy living information and interactive tools such as Symptom Checker, a local physician and health directory, pill identifier, and medication reminders.

## A note from Cheryle....

Once again, the newsletter is going out to you much later than I had planned. It's been a very busy and sometimes rough time, since our last meeting in July. Some of you know that my husband, Frank, retired on June 1st. We both are enjoying him being home, but nevertheless, it is an adjustment. We had a little garden and canned tomatoes and pickles. We are also working together on our family history. Now, I need to finish sewing a dress for my sister-in-law's 60 year old doll, before we drive to Indiana for genealogy later this week. Her great-granddaughter wanted to play with the doll, but it's embroidered organ-dy dress was crumbling to pieces. I've drafted a pattern, since none of the modern doll patterns work, and I have a piece of vintage floral fabric that will be perfect.

I had several doctors appointments scheduled in August, including a routine colonoscopy. A week later I ended up in the ER and admittance to the hospital with a severe infection in my intestines. After 4 days and 3 different antibiotics, I was able to go home.

Shortly after that, we attended TMA's patient conference in Louisville and thoroughly enjoyed the sessions. Many of the sessions on DM, IBM and PM were taped and the videos are now available on the Myositis.org website. On the opening page click on 'Visit The Myositis Library'. Next scroll down to Video library to see the taped sessions & go to 'Presentations' to see the meeting presentations and handouts. Next year's conference will be in Minneapolis. A few scholarships will be available for those who qualify.

So that is a bit about what's going on in my life. Hope to see you in November.



*Pixies's Perspective*

Support Group Meeting July 28, 2018

Two Amazing Presentations!

**BriovaRx with Todd Dixon and Matt Johnson**

&

**Dr Stephanie Palma, Physical Therapist with Benchmark Physical Therapy**

I wish I could give you a master class covering each of these presentations. There was so much information, generously given, including videos and demonstrations, that I can only say - keep these names in your speed dial!

**Dr Stephanie Palma** is a **Neuro Certified Movement Specialist** in Dahlonega, Georgia, who has been working since 1976 with patients recovering from stroke, Parkinson's, brain injuries, accidents, military injuries, seizures, and muscle diseases - she has seen it all. She treats two of our IBM members, Tom Cox and Augie DeAugustinis. They asked Dr Palma to describe the meaning of an Exercise Rx and to share the benefits they have experienced using E-STIM bands (Electrical Stimulation) that are used in hospitals and by physical therapists trained in their use. Tom and Augie each have sets of these units that they own and use in their homes.

**A couple of Dr Palma's most important or inspiring quotes:**

Exercise does NOT increase CPK levels

Exercise can improve mood and enhance quality of life

Exercise can improve muscle function, endurance and volume of muscles. It can increase mobility during the progress of myopathy diseases

Expect to be tired and maybe a little sore or generally 'non-functioning' from even 5 to 10 minutes of Physical Therapy or E-Stim. It is normal for a day BUT if it lasts 2-3 days or if it is too much fatigue or pain COMMUNICATE with your PT!

It is important to keep as mobile as possible for as long as possible in your life

General exercise is good for mood enhancement and neurological stimulation. Strengthening exercises however, must be targeted to the desired functional outcome and to exact muscle areas surrounding the weakness. An Exercise Rx is a targeted PATTERN of exercises written by a Physical Therapist for each patient. It is specific to each problem area and motion required. Even though PT and muscle stimulation cannot restore or improve areas of muscle which have been damaged by IBM or another form of Myositis, they can stimulate the surrounding unaffected areas to increase strength and create better movement and function.



Pixies Perspective, continued

In order to help us understand how far research and technology have progressed and how much exercise can help, Dr Palma described in detail how muscles work - by using different types of fibers. Muscle movement starts in the brain with signals that flow down nerves to trigger muscles to contract in patterns. This is the reason she says she considers especially IBM to be a neurological as well as a physical problem) Healthy sections of muscle can lay fractions of an inch from a damaged section. Targeted areas can be strengthened by specific specific combinations of exercise or by electrical stimulation that require detailed understanding of how complex movement is.

Dr Palma demonstrated the 5 different stages of muscle firing that it takes to make just one stride while walking - the buttocks (gluteus maximus and medius), hamstrings and quadriceps (surrounding the thigh), and calf muscles surrounding the lower leg, some of which are also connected to the foot.

The most amazing part of Dr Palma's presentation was her description and video of the E-STIM L 300+ system. When used on different parts of the body which are impaired - from diaphragm (to stimulate breathing after spinal injuries) to stimulation of arms or hearts or legs - it sends electrical pulses which trigger muscle contractions at proper times. We saw veterans and stroke survivors who were being helped to walk. Tom Cox activated one of his personal bands on his arm. He told us that by using these 3-4 times per week and working with Dr Palma he can do things that he had not thought he would be able to manage anymore. He and Augie have units for their legs as well. You will have to ask them about any sort of insurance coverage! If they found it.

Finally Dr Palma mentioned a system called Whole Body Vibration balance system which can also improve skeletal muscle mass. It was created to help astronauts who sometimes have muscle weakness post space flight. It is also used for Parkinson's patients and is helpful with osteoporosis. There are plates you can stand on in hospital or PT settings. Small one can be used on a table for arms etc. It was time to break up the meeting at this point so I have very little information about this device.

Please feel free to talk to Dr Palma 770.722.2288 or Tom Cox 404.421.6614 if you have questions.

**BriovaRx Speciality Pharmacy**, Owned by United Health Care  
IVIG Home Infusion - Information and Options  
**Todd Dixon** and **Matt Johnson**, Infusion Specialists

Many patients with Dermatomyositis or Polymyositis are successfully treated with IVIG infusions, alone or together with other medications. Some IBM patients have also experienced benefits from IVIG. .



As common as it is, few of us know what it is, how it is manufactured or whether insurance will pay for such expensive treatments. Matt and Todd gave the support group a master class covering IVIG formulation, manufacture and clinical infusion procedures. Matt also provided valuable insurance tips. Together they are knowledgeable, experienced and generous with their help and spoke of how BrioVaRx offers personalized care.

We were told that IVIG is an immune system booster. It is used for over 90 conditions, though only about 8 of those are 'indicated/authorized' by the insurance companies. This is what makes the 'off label' (but also effective) use for myositis and other chronic care so difficult to get approved

Collection, Manufacture and Procedure basics:

Citizens go to their local blood collection/donation centers. Donors are medically screened and paid to donate plasma. The plasma contains antibodies needed to help people fight their conditions. The plasma is cleaned and filtered with an FDA approved process which can take one year. There are approximately 8 different brands of IVIG available on the market today. Each is mixed with a slightly different set of stabilizers (for shelf-life needs, none of which includes sugar because of diabetic patients). The vials are then sent to speciality pharmacies for local storage and distribution. It can take up to 600 donors and \$20,000 to produce one vial of IVIG!

Some patients take their IVIG at hospitals or infusion clinics associated with hospitals. Some people don't know that the infusion can be done at home - DEPENDING on your insurance guidelines. Rather than a clinical infusion setting, BrioVaRx brings the IVIG to you in your home. Each trained RN infusion nurse (who has a background check!) has all the equipment necessary and remains with the patient for the entire procedure. Depending on the physician's order the infusion (an IV drip) can take 3 - 6 hours. Frequency also depends on the condition, patient's body weight and the doctor's orders.

Todd also said that some patients do not respond to or benefit from IVIG. (Though he suggests that 'plasma exchange' - similar to dialysis - might be an option) And remember that your physician may prescribe other medications for your condition as well as IVIG.

Insurance coverage:

Matt noted that if you have Medicare or Tricare without a supplement it is required that you take the infusion at a hospital infusion clinic and use Medicare part B.

I did not find any information in my notes about Medicaid patients.

Insurance coverage calculations go something like this -

Ask your physician whether he would approve of home infusion. If yes, then the doctor sends the referral and relevant medical documents, lab test information, etc to BriovaRx. Their clinical team evaluates options and resources depending on the insurance information supplied by the patient.

BriovaRx is experienced with the various 'prior authorization protocols' of different insurance companies. They have a resource team which can discuss with the patient 'out of pocket' options, deductible options, secondary insurance options, other co-pay options and/or requirements. The team knows various 'insurance verification' requirements of different insurance companies. The team can negotiate with the insurance company and also guide you through any appeals. They can even help you fill out 'financial hardship' applications.

It is important to note that there is NO obligation to use Brovia after you have asked for information or help.

Matt also stressed that pharmacy companies are not allowed to promote their assistance programs unless patients ask! Even if you are working on this yourself with your insurance company, pharmaceutical company or with the physician's insurance nurse (who knows every single insurance company they deal with and should probably be paid a bigger salary for the frustration!!), you should ask: "Do you have or do your patients use any Co-Pay Assistance, Patient Foundations, or have any Financial Assistance programs? How can I contact them? (there are some just for non-insured patients to help them get meds and some for people whose co-pay amounts are high).

Todd and Matt reassured us that they are not just a pharmacy, they are a patient resource company. They act as liaisons between chronically ill patients along with their doctors and the insurance companies.

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Both presentations were very good and the speakers so knowledgeable and generous with their information. By sharing their experiences and training has been a gift to us all. Our support group appreciated every gem of information they provided. They will be happy to answer any questions. ~~~ Pixie

For more information on BriovaRX call Matt Johnson 470.201.0777

~~~~ **A very big thank you to Pixie Allison** ~~~~

Pixie works very hard after every meeting to put together the summarizations of our speaker presentations for our newsletter. This past meeting we had two speakers and each covered an abundance of information. Pixie once again, has done an incredible job covering the information. First it's to help refresh the memory of those who heard the speakers at the meeting, but secondly and even more so, for those who could not attend, to be able to read her perspective and benefit from the information.



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



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**Cold and Flu season is just around the corner.**

**Don't forget to get your Flu, Pneumonia & Shingrix vaccines!**

**Those of us who are immune suppressed need all the help we can get!**



## Great News on Meeting Room Space!

It's not been an ideal situation for us to have to bounce back and forth between libraries based on availability.

Bob Wildrick of Blairsville has been in touch with an Elder at his former church, Covenant Presbyterian, on Rock Springs Road in Gwinnett County. It's a good location just off GA 20 and I-85 .They have unanimously voted to host our group, once their new fellowship hall is completed in 2019. We'll keep you posted.

Thanks Bob!

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