Myositis Newsletter

THE MYOSITIS ASSOCIATION

Georgia Myositis Support Group Newsletter

~Next Meeting~ July 28, 2018

Please note: DIFFERENT LOCATION!!!!

Five Forks Library
2780 Five Forks Trickum Road, SW
Lawrenceville, GA 30044
10:30am-2:00pm

Reservations are a must!

Please call Cheryle 678.386.2435
or email CheryleMiller@comcast.net
By July 23rd

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Agenda

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

Our first speaker at 11:00am
Todd Dixon
Home IVIG Care Specialist
BriovaRx Infusions

Lunch

Our second speaker at 12:30pm
Dr Stefanie Palma, DPT
Board Certified PT Specialist

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Breakout Sessions 1:30-pm-2:30pm

Volume 18, Issue 2

2018
Meetings

Jul 28
Nov TBA

New Members
Attending
In February
Alan & Rhonda Duncan
& Lucy Viscaino

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No new members
Attended in April

Inside this issue:
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2018 Annual Patient Conference

Louisville KY

September 6th~ 9th

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Financial Aid

Some funds have been made available to assist those who might otherwise not be able to attend.

If you have not yet registered for the conference, would like to attend ,but cannot afford to, you are welcome to apply. The financial assistance, if granted, will cover 1 hotel room and conference registration fee. No travel expenses are included. Some meals are included in the registration fee, no additional meals provided.

To apply send an email to **TMA@myositis.org** , to provide this information:

1.Your name (name of myositis patient)   2. Disease type and when diagnosed

3. Email address   4. Mailing address

5. Primary phone number   6. Cell phone number

7. Have you attended a TMA conference in the past? If yes, what year?

8. In 150 words or less, why do you want to attend and how will the financial aid help you?

Do not attach any records or materials.

Deadline is 5pm, June 22, 2018   A decision will be made by July 10, 2018

Shingrex Vaccine

Finally, those of us who are immune suppressed can be protected from Shingles!!

Shingrix provides strong protection against shingles and the resulting nerve pain. It is not a live virus, so it is not contraindicated if you are on immune suppressant medications. It is administered by an injection in the upper arm, either by your doctor or at your pharmacy. A second injection is necessary between 2 to 6 months after the first.

You should get Shingrix even if in the past you:

*Had shingles

*Received Zostavax

*Are not sure if you had chickenpox

Many private health insurance plans and Medicare Part D cover shingles vaccine, but there may be a cost to you depending on your plan.

Products That Benefit

Magnetic Jewelry Lobster Clasps

Dsmile Jewelry Lobster Clasps fasten on to your necklaces or bracelets , so that you can use the center magnet to easily put on your jewelry. This product is very useful if you have arthritis or difficulty with fine motor skills.

Amazon.com 10 pieces for $7.99

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Drive Nitro, *TALL* 4 Wheel Rollator

- Approximate user height: 6' and above
- Height adjustments: 36"-41"
- Flexible, removable backrest for more comfort
- Features front side removable pouch to carry your belongings
- 10" front wheels easily traverses most obstacles both inside and out
- One handed folding for better ease of use
- Weighs: 17.5 lbs.
Weight capacity: 300 lbs.

$219.95 **JustWalkers.com**
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Helpful Apps

Here are a few phone apps that you may find useful.

WheelMap This app helps to list buildings and public spaces as fully accessible, partially accessible or not accessible for wheelchair users.

WheelMate Lists parking spaces and toilets as to their level of accessibility.

Uber Helps you choose a wheelchair accessible "taxi" ride.

Tecla Helps users control their devices & electric wheelchair with motions, eye blinks and puffing.

Helpful Resources

Patient Advocate Foundation (PAF) (800.532.5274, www.patientadvocate.org) offers a range of services for patients facing medical debt crisis issues, including referrals to charity care and assistance with setting up payment plans. If a patient has a diagnosis that qualifies for copay assistance, the patient may be referred to PAF's Co-Pay Relief Program to determine eligibility.

Needy Meds (800.503.6897, www.needymeds.org) provides a prescription savings card that enables those eligible, to get discounts in certain medications at participating pharmacies throughout the nation

RxAssist.org offers a database of drug assistance programs provided by pharmaceutical companies that enable patients to receive assistance with numerous medications.

The Partnership for Prescriptions Assistance (www.pparx.org) also helps people find prescription assistance programs, as well as free or low cost healthcare clinics.

Medicare Rights Center Hotline (800.333.4114) is available to seniors or to those with a disability. When using the service, callers can learn about Medicare and other resources available to them for obtaining public health insurance. The Hotline also offers assistance for dealing with medical bills.

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Helpful Website ~Drugs.com

Drugs A-Z look up your medication for information and side effects

Pill Identifier Need help to identify a pill? Identify by shape, color & numbers.

Interaction Checker. List your meds and to check for interactions between your meds and also interactions of foods.
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Pixies's Perspective

KIT Meeting April 14, 2018

Bob Goldberg on TMA's Mission

After leading The Myositis Association for 16 years, Bob Goldberg, Executive Director of TMA, will retire later this year. His dedication and wealth of experience has enriched and expanded the organization in important ways. The Board of Directors is currently searching for a new Executive Director, who will be introduced at the 25th Annual Conference , September 6-9, in Louisville, KY.

This summer, Bob is traveling around the nation, visiting Support Groups like ours, for three basic reasons. Firstly to encourage people who can, to attend this year's Conference. Secondly to give us a clear and comprehensive description of TMA's mission in all its forms. Thirdly, and most importantly, to personally listen to the concerns, questions and comments of patients, families and caregivers - many of whom cannot make it to the conferences.

He spoke of **Four Missions: Education, Support, Research and Advocacy**

Education and Support of patients and physicians. Frequent newsletters to patients from TMA, publishing a new edition of 'Myositis 101', a basic handbook for newly diagnosed patients and their families, includes topics such as psychosocial aspects of dealing with chronic disease. The Physicians Guide to Myositis aimed at educating doctors about the disease (including resources for physicians). Other sources are theTMA website, The Myositis Association social media site on Facebook, an 800.821.7356 phone number you can use for any questions or concerns you might have about your disease. You can also email tma@myositis.org with questions.

Research funding to find a cure and for discovering/developing treatments. TMA has been funding research since 2003 with the total amount of funding at just over $7 million. Rare disease organizations are small, but can still be very influential. We have funded 55 grants and fellowships covering all three forms of Myositis as well as Juvenile myositis. There are pilot projects which have led to more research. At present there are 5 large clinical trials going which were seeded or suggested by this research. These trials are a way to get the Pharmaceutical industry interested in treatments for rare diseases. There are more new drugs being tested or used for myositis now than there ever have been. And even if a drug is only passes as a treatment for another neuromuscular disease that means it can be tried off-label for our type of muscle disease care.

There are three trials going on for IBM treatments. One which tested a gene therapy treatment that has finished and is now looking for funding for the next stage. TMA contributed $400,000 of the $1.5 million needed for that trial. An IBM patient donated $400,000 of his personal funds as well. You can go to the website and click on Research then Clinical Trials to get a list for all current trials for all forms of myositis research. $500,000 may be funded this year leading to 4-5 trials in 2018.

The volunteer Medical Advisory Board this year includes 22 physicians, many of whom come from other countries. The yearly Conference is an opportunity for these doctors to meet and share insights and breakthroughs. There are also 1000 doctors in the TMA data base who have an interest in myositis. Grants are evaluated by the board of physicians and then the volunteer Board of Directors makes the final yearly decisions. Last year there were 21 applications and TMA funded 3 of those.

Advocacy to create awareness of the disease among the public and for physicians. A Visiting Professors Program which for the last 5 years has funded presentations at 40 medical schools so that physicians in training can get accurate information about a disease they may not ever have heard about. There is a booth at the yearly Neurology Conference. Physicians can get up to date information about this disease and the research which needs to be done.

Myositis Awareness month is May and TMA will supplied a template of a letter to the editor to send to newspapers and TV stations to help people become aware of this disease. There is also a news-release form letter that can be sent to local papers.

2018 Piedmont Healthcare Community Healthcare Class Schedule

Advance Care Planning ~ Free Classes!!

Piedmont Atlanta Hospital, July11, October 10 (classes 11am-noon)
1968 Peachtree Rd. NW, Atlanta Building 77, Classroom 7

Piedmont Newnan Hospital, August 28, November 27
745 Poplar Rd., Newnan Conference Room #1 ((1pm-2pm)

Piedmont Fayette Hospital,July 11, October 10
Classes are at Fayette County Chamber of Commerce Room # 205(2pm-3pm)
600 W Lanier Ave, Fayetteville

Piedmont Mountianside Hospital, Education Room, July 17 (2pm-3pm)
1266 GA-515, Jasper   AND
Community Center Ellijay, September 18 (1pm-2pm)
824 Industrial Blvd, Ellijay

Piedmont Newton Hospital, July 17, October 16 (1pm-2pm)
Physicians Office Building at Newton Hospital Auditorium
4181 Hospital Dr. NE, Covington

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Revivify

I was asked by TMA, to sum up our support group with one word. I chose the word revivify. It means to give new energy and vigor or strength to someone. I feel that is exactly what we try to accomplish with providing support to each other as we each struggle with accepting our ‘new normal’ with myositis.

Thank you for making this support group one of the best!
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THE MYOSITIS ASSOCIATION

www.myositis.org

If not yet a member,
Please join TMA!

TMA's New Website!

If you haven't logged on to TMA's website for a while, log on to www.Myositis.org And check it out!!

If you are not a member of The Myositis Association (TMA), please consider joining. There are no costs to become a member and be on their email and mailing lists. In addition to the wealth of information on the site including research information, educational videos, past patient conference sessions and a blog, you will receive a copy of TMA's Quarterly newsletter, **The Outlook**, that is chock full of articles on research, clinical trials and studies. If you would like to share your myositis journey with others, there is also a section of Show and Tell, that highlights a patients experience.

Join today! Online at www.myositis.org or call 800.821.7356