



Myositis Newsletter Newsletter



THE MYOSITIS ASSOCIATION

Georgia Myositis Support Group Newsletter

Volume 17, Issue 1
Spring 2017

Next Meeting ~ April 1st, 2017

10:30am-2:00pm

Chamblee Civic Center

3540 Broad Street

Chamblee, GA 30341

*Soleo Health is providing lunch,
Reservations are a must!
Call Cheryle 678-386-2435 or
email CheryleMiller@comcast.net
by March 24th*

2017
Meeting Dates
April 1st
August 26th
November 4th

New Members

New members
attending in January
Jim and Jill Dooley
Bob and Anne Wildrick
Welcome!



*Remembering
Gene*

Gene Hatfield

August 28, 1944-January 12, 2017

Gene struggled valiantly with IBM. Although he was too ill to attend recent meetings, we will miss him and want to dedicate this issue to him and also to his sweet wife, Carol, who has been so helpful and supportive at our meetings.

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MYOSITIS AWARENESS MONTH

“What’s That Thing You Have Again?”

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This year, we will spread awareness of Myositis, by starting at home. I’m writing Myositis Awareness information sheets for each form of myositis. These include information on your specific disease, and are for you to use to hand out or mail, to family, friends, neighbors, a cashier or the fella who rotates your tires! I have chosen the title **“What’s that thing you have again?”**

At first, I wondered if this was a good title for the information sheets. This is the sentence that I have frequently heard in the past, from so many people. Two weeks ago, I was in Tennessee attending a bridal shower for my niece, when my very own sister asked me in those exact words, “What’s that thing you have again?”. I laughed and told her about the information sheet that I was writing and I told her she would get the first copy! That reassured me, that the title is the right one and I think it’s a also a bit intriguing. I wanted it to be something catchy, something that really might encourage someone to read further on.

Copies will be available at our April 1st meeting. If you cannot make it to the meeting, please let me know how many copies you would like and I will mail them before May 1st. **If we each give out or mail a minimum of 10 copies, as a group, we are really making a difference in awareness of our disease! Awareness is the first step towards a cure!**

A prize will be awarded for handing out/ mailing out the most info sheets during the month of May. More details at our meeting.

Cheryle





Products That Benefit

MedCline Reflux Relief

MedCline.com

MedCline is a pillow system composed of two pieces: an incline pillow and a body pillow. It was validated in clinical trials that the inclined side sleeping position is found to be the most effective for relieving reflux symptoms. The armhole through the pillow makes for a more comfortable sleeping position.

Different sizes are available based upon your height and weight.

Wedge base \$178.00 or Wedge with Body Pillow \$296.00 Free shipping!



Glider Gloves

Touch screen gloves that provide warmth. Spring is almost here, but now is the time to consider buying, as they are now **on sale!**

Winter style sale \$24 (regularly \$29.99)

Lighter style sale \$18 (regularly 24.99)

Made with conductive threads woven throughout, instead of just in fingertip areas like other gloves, so they are easier to use.

Glidergloves.com 877.433.9908





Helpful Information and Websites

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### *Doctor, Your Patient Will See You Now*

*Gaining the Upper Hand In Your Medical Care*

By Steven Z. Kussin, MD

I've written a review on this book before, but it is one of my favorites and want to repeat it particularly to let our new members know about it. It is chock full of information, some of it rather shocking. ( for example, some of the things that go on during your hospital stay) I wish it had been available when I first became ill, to inform me and help me navigate and help me manage my healthcare. The book also includes several pages of the best medical websites.... Much more reliable than "Dr Google"

~Cheryle

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IGLiving Magazine

For those members taking IVIG as part of their medical treatment.

IGLiving is a free magazine, published bimonthly, and is available either online or mailed to your home.

Although it is written for anyone taking IVIG, some articles are written for specific diseases other than myositis. There are also myositis specific articles as well. The January-February issue, for example, has an article on ***Managing and Treating Myositis-Related Interstitial Lung Disease***

Education * Advocacy* Support

For more information : www.IGLiving.com



Pixies's Perspective **101 Mobility**

The January meeting presentation by Chris Doster and Steve Donovan, of 101 Mobility, showed that there are generous people in the world. They are eager to help others with unique needs to live as full a life as possible. They shared their personal and professional experience in this field, with detailed information and advice - and make house calls! They promise to help you find the best total mobility solution, whether it is commercial or residential, large or small, inside or outside or when you are in your car or truck!

101 Mobility is #6 out of the top 50 mobility companies in the US. The company has stores in 50 states. They strive to

Educate - The 3 lines of product they use are based on quality and reliability (based on fewer repairs and availability of replacement parts) (shared their honest opinion of a competitor, Acorn products that you may have seen advertised and does not recommend - too many repairs needed and too many plastic parts)

Make Detailed Measurements - unique to each situation, budget and physical need

Provide Free Estimates - so you know what your options are before decisions are made

Their years of experience showed whenever they mentioned the VA rules, their contract with the VA, the ADA compliant rules, individual community housing HOA rules, workers comp, building codes - and the solutions that they had devised to work with each situation. There seem to be solutions for problems as small as a 2" riser and as large as a power chair lift for a truck. There are solutions for different styles of houses and individual disabilities and custom needs. For example: stair lifts, car modifications, and ramps.

Stair lifts for straight staircases, 'curved' staircases (meaning with angles and landings) and custom needs.

The track is covered under the rail - the safest method - the seat height is adjustable, carries up to 400 lbs, has footrests, does not impede others who walk on the stairs, has safety switch at the top (lift will not work until person is seated and uses the control), other safety features, has batteries which charge nightly (allowing 15 to 20 uses even with power outages) It charges nightly using a regular outlet. 5 year warranty covers 1st year of maintenance, 5 years for the motor, gear box and parts. You can rent straight stair lifts. They will buy back straight stair units, if under 2 years old and it passes their inspection. You can sell gently used lifts. (I include these facts not only to give you a report on what was presented at the KIT meeting but also to give you information so you can make comparisons when contacting other companies.)

Car modifications They offer wheelchair and power chair attachments (cage or lift) sold by make of car or truck. Automatic button inside to lower the chair or manual release. Can do demos at your home and can do the needed adaptations.

Ramps 1. Modular, 2. Threshold for 1 - 3" bumps. They offer 2ft to 12ft portables which fold for transport. Ramps can be tricky - to get the right rise for the space, for the HOA rules (some don't allow them in the front yard so they may recommend one in the back yard) and for cost because of the length of some of them. To be ADA compliant, the ramp must be made 1 foot long per 1 inch of rise. Sometimes this makes for problems if a yard is not big enough for the proper length. If a ramp is not feasible (for example if one is needed in a garage) then they can build a Vertical Platform Lift . These require a 5x5 concrete slab which these guys are also happy to build for you! They also mentioned that they also do modifications on entrance or internal doors when needed for any of these products.

For those of you who could not attend this meeting (maybe you can't get out easily because you don't have any of these great mobility products!) I hope you are encouraged and enlightened. This company has a wealth of information and a generous heart. Phone **770.791.2000** or **www.Atlanta.101Mobility.com**





2017 Patient Conference

San Diego California

September 7-10

Sheraton San Diego Hotel and Marina

\$125 per night, call 619-291 2900

**Registration is now open for the hotel and conference.
More information online at Myositis.org.**

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

Do you shop online at Amazon.com?

When you sign up for www.Smile Amazon, 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!





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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 and at the January meeting, some members exchanged phone numbers and email addresses. Since our meetings are only 4 times a year, this is such a good idea. I hope more members will buddy up and contact each other throughout the year.

This week, I had one member contact me, to offer a ride to another member, who lives nearby. This is such a wonderful gesture, particularly if they are bringing someone who couldn't otherwise attend. If you would be willing to provide a ride to someone who lives close by, please let me know. ~Cheryle

