



THE MYOSITIS ASSOCIATION

Washington, D.C., Maryland, Northern Virginia and
Delaware Support Group Newsletter

May 2015

Look around, as I drive to and fro I am reminded just how beautiful spring can be. With the cold, snow and windy weather behind us it is so rejuvenating to see the daffodils, jonquils, tulips and flowering trees decorate the yards and highways. They are signs of warmer days and good things to come. Enjoy!

On February 7th we were fortunate to have Katherine Falcone, President of the SOS Group Inc. (kat@sosgroup.info) or (www.sosgroup.info). SOS (Safety Outfitting Services) helps to increase independent and comfortable living by providing home modifications and medical equipment for people of all ages. They are licensed in New Jersey, Pennsylvania working on getting licensed in Maryland. They serve as a consultant and will give free estimates. SOS donates a portion of its sales to Myositis and they attend the Patient Conference each year. We were able to watch a video and have a great discussion of “Home Accessibility Solutions”. One of their specialties in safe solutions for the home is their modular ramp system that can be rented or purchased. It can be bi-fold for indoor or outdoor and portable. The construction material varies from Aluminum, Steel, Pavers or stone, suitcase ramps to QRamp.



Aluminum Ramp Fig.1



What are your ideas?



Figure 2 Stair Lift

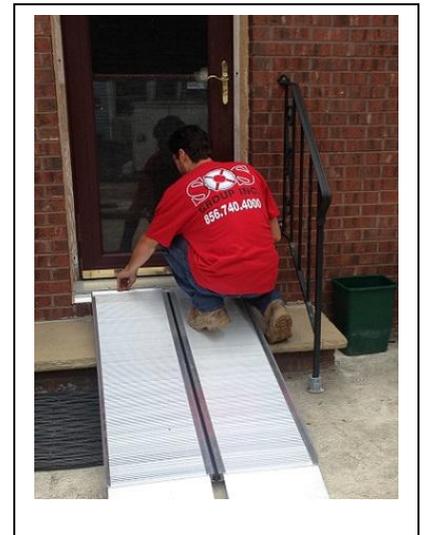


Figure 3 Bi-Fold Ramp



Fig. 4 Grab Bars

Rentals can be a short term option for complete accessibility to home or office (decks, porches, stairways, or interior space). Their lifts and ramp rentals provide the safe, easy, and affordable access you may need. SOS Group Inc. services also include:

- Medical Alert Systems
- Zero/low entry showers
- Walk-in-bathtubs
- Scooters/rollators/ walkers
- Patient wheelchair lifts
- Auto Lifts
- Pool Lifts
- Widened doorways
- Adding bedroom and bathroom to the main level.
- General construction / renovations of all kind.
- They install all of their own services.

Much was on display for us to see firsthand. Not only that, but Bitsy brought devices that make life much easier for her.

- Half step
- Aid to put on socks
- Rollator
- Toilet Riser
- Kitchen gadgets
- Foam Cushion

NOT TOO EARLY TO THINK ABOUT THE PATIENT

CONFERENCE *SEPTEMBER 10TH-13TH, 2015*

The patient conferences to me are very important. Life can be like swimming up the rapids without a life jacket and you feel like you're sinking. Then at the conference with each day and each presentation you are given the survival skills to improve your situation and make your life the best it can possibly be. Each year is better than the year before and presentations geared more specific to your type of Myositis. Topics include information on the latest research, nutrition, exercise, medication, assistive devices, treatment, breakout sessions for the specific types of Myositis, cancer, heart disease and dysphagia risks for myositis patients, how to live with chronic disease and so much more.

Those with myositis face the difficulty dealing with a chronic illness, plus the extra challenge of having a rare disease most people have never heard of. Because the disease is so rare, it's hard to find others who understand what you are going through and the challenges posed by myositis. At the conference you are surrounded by people who immediately understand what you are going through. I learn as much from the other attendees as I do from the speakers. How the attendees meet each challenge is shared and we have a Medical Advisory Board of 20 physicians working for a cure. They too will share their findings.

Please join me this year in discovering ways to outlive this disease the best way available.

2015 Annual Patient Conference



Caribe Royale

8101 World Center Drive
Orlando, FL 32831

Phone: 1-888-258-1501

www.thecaribeorlando.com

Book your room NOW!

Back to the Future

We're back! TMA's 2015 Annual Patient Conference is back at the Caribe Royale, site of TMA's 2012 Annual Conference. Why are we back? Because the Caribe Royale is a splendid facility that is ideally suited for those with physical limitations. TMA members had a great experience at the Caribe in 2012 and we expect nothing less again this year. All sleeping rooms are spacious suites and there are 2-bedroom villas as well – all at very reasonable rates. Suites are \$109 per night and the villas are \$169.

Now here are opportunities to make friends and share how we are adapting to our situations. Mark your calendar!

2015 SUPPORT GROUP MEETING DATES – at 1:00 PM – 4PM The first Saturday of the following months. Hosted by the Support Group.

Meetings are held at Our Lady of the Fields, 1070 S. Cecil Ave., Millersville, MD.

- May 2nd
- August 1st
- November 7th

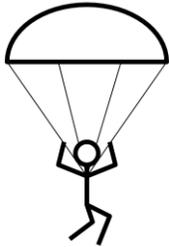


Please come. We all face the difficulty dealing with a chronic illness. At the meeting you have others who understand what you are going through. Research has shown that people who receive support from a social network cope better, feel more in control and have a better outcome than those who are isolated. We need you!

Are you curious to know what's happening as a result of the recent TMA survey?

Nearly 800 members responded with suggestions for emphasis by TMA. For an overview of how the responses went you can go to: <http://www.myositis.org/about-tma/2014-member-survey>. Those responses were then condensed into 5 separate areas and the TMA Board of Directors, along with members of the TMA staff, were assigned to these 5 areas (work groups) to brainstorm and otherwise work on solutions or programs for improvement. The five general areas are: Research, Support Groups, Education/Information, Awareness, and International. These groups have been meeting

over the phone lines and via e-mail feverishly discussing ideas to enhance the work of the TMA organization (Staff and Board Members). Results, at least preliminary, will be reported at the Annual Patient Conference in September, 2015, in Orlando, FL. As always, TMA is eager to hear good ideas for improving services to its members; to do so sent an e-mail to: TMA@myositis.org or mail your suggestion(s) to: The Myositis Association, 1737 King Street, Suite 600, Alexandria, VA 22314.



Strength doesn't come from what you can do. It comes from overcoming things you once thought you couldn't.

Let me know if there is something you'd like to see in the newsletter. Call anytime Bitsy Anderson 410-987-9407 or email terrybitsy@verizon.net. Great things happen when we put our heads together.