25 YEARS AS YOUR · MYOSITIS ASSOCIATION ·

THE MYOSITIS ASSOCIATION

AL, MS, FL NW KIT
August 2019 Newsletter

Now in our 26th year!

Our November 22 KIT will be another conference call using ZOOM.

More information will follow

TMA's Offices have moved! As of July, they are located across the street at:
2000 Duke Street,
Suite 300

Alexandria, VA

22314

Phone: 800-821-7356

Or 703-553-2632

TMA@myositis.org

WWW.myositis.org

Nearly 500 attended the 2019 TMA Conference in Minneapolis September 5 – 9 resulting in another great success with many new topics covered in the presentations offered. Some of the more well attended presentations were repeated so attendees were able to fit all chosen sessions into their schedules. The presentations are available on the TMA website, many in video format. Viewing these presentations can prove to be very informative even if you attended the conference. Take a look!

Once again the presentation by the **Medical Advisory Board** was well attended. TMA is fortunate to have 23 of the world's most respected myositis experts serving as medical advisors. Each board member briefly introduced themselves and shared what research they're pursuing. Attendees were then invited to direct questions to the board. As always, this session gave an excellent opportunity to get members' questions answered and you can benefit from these questioners by viewing this session on the website. And you can pause, backup and repeat if desired. WATCH IT!! 😉

The **August 22 KIT** was a ZOOM conference call and unfortunately only three households from our AL, MS, FL NW KIT joined our conversation. (There are over 150 TMA members in this KIT area.) LaDonna Johnson, Member Services Manager of TMA also participated as a show of support for our members and to offer assistance with ZOOM if needed.

This format of using your computer, tablet or phone as a way to communicate with other members allows face-to-face conversation without the awkward "talking-over-each-other" that often occurs in traditional phone conference calls. With the entire states of Alabama and Mississippi and the Panhandle of northwest Florida comprising the locales of our KIT membership, physical meetings close-to-home for all are impossible to accomplish. When TMA added the availability of ZOOM conference calls, it provided the opportunity for members from hundreds of miles away from each other to "gather" in one venue without even leaving home. **We will try ZOOM again and a reminder about how to join the November 22 meeting and the specific time and login information will be sent prior to November 15th.**

The following is from the TMA website:

Research has shown that people who receive support from a social network cope better, feel more in control, and have better outcomes than those who are isolated. Those who live with myositis, however, face the difficulty of dealing with a chronic illness plus the extra challenge of having a rare disease that most people have never heard of. Because the disease is so rare, it can be hard to find others who understand what you are going through and the challenges posed by myositis.

Keep in Touch (KIT) support groups provide members the opportunity to get together with others in their area and share concerns, friendship, and ideas. As a member of The Myositis Association, you are invited to join the TMA KIT support group network. When you choose this TMA service, your name, contact information, and diagnosis will be added to the list of support group members in your area and will only be shared with those in your specific KIT support group.

Hopefully each of you will strongly consider joining our next ZOOM KIT on 22 November. Please accept our hands of friendship.

As a reminder, the ZOOM host and each participants' picture will show in windows on your screen and with a 'click', you can request to speak. The host recognizes speakers individually. Let's try to overcome the obstacle of distance with a well-attended ZOOM meeting. Our TMA Conference theme was **Who you are matters! We are in this myositis fight together! Please Join us! Questions? Call me at 850-279-4306 after 23 October.**

Other TMA Conference news:

There were 18 exhibitors at the conference this year and most were also Conference Sponsors. In addition to having their tables set up in the hallway with pamphlets and advertising gear, several of the sponsors gave presentation about their businesses. Among them were Wheelchair Escapes – Accessible Travel with tips on travel regardless of physical restrictions. Updates on myositis clinical trials were presented by Corbus Pharmaceuticals, Orphazyme A/S, CSL Behring, and Ra Pharma. They explained how pharmaceutical companies choose their research projects, identify research sites and coordinate with researchers and those affected by the disease. Representatives of five different Specialty Pharmacies explained what IVIg is and how it is used for those with myositis including addressing the access challenges those with myositis face when trying to use IVIg medications.

Additionally, three ladies from Target, the Principal Technical Designer, a Senior Product Designer and The Director of Kids Technical Development presented a program about their great success with their adaptive clothing line for children called *Cat & Jack.* Members learned about the successes and challenges in building a fashionable adaptive line and were able to offer suggestions in an open discussion with the designers about their move into **adult adaptive clothing**.

From the OUTLOOK - Fall 2019 Quarterly Newsletter:

Pfizer is currently seeking adults 18 – 80 years of age for a dermatomyositis clinical trial. This clinical trial will assess the effectiveness and safety of an investigational study drug compared to placebo. The study drug is a type of drug called a biologic and is given by infusion. The clinical trial is currently active and enrollment is open at multiple sites across the United States. Qualified participants will receive all study-related care and study drug (or placebo) at no cost. Learn more at: www.pfizer.com/science/find-a-trial/nct03181893.

Bristol-Myers Squibb is currently recruiting adults with active dermatomyositis or polymyositis for a clinical trial. The goal is to evaluate the effectiveness and safety of a study drug called ***abatacept***, in combination with standard medicines in improving symptoms of active myositis. The effectiveness of this combination therapy will be compared to standard therapy for myositis.

This clinical trial is underway and aims to enroll 150 patients over a three-year period. Multiple study sites are available throughout the US and abroad. Participants will first receive either ***abatacept***, the study drug, or a placebo via a weekly injection under the skin for 24 weeks. Then, all study participants will receive ***abatacept*** for 28 weeks. More information on this clinical trial can be found at www.MyositisTrial.com.

P.S. If you did not receive OUTLOOK in the mail, it can be viewed on TMA's site.

Please contact me if you have any questions **or suggestions** about our KIT, or the November ZOOM meeting. I will do my best to get answers to any questions you may have about TMA, the TMA Conferences, MYO-Connect or any other subject you would like to address regarding our group, TMA or Myositis.

Madge Chambers, leader

H-850-279-4306 *** C-478-335-0420 *** nwftmakit@cox.net