



**Nov. 15, 2018**



THE MYOSITIS ASSOCIATION

# Northwest FL KIT November 2018 Newsletter

**Welcome new and old friends!**

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***Our February KIT  
will take place  
February 21 at the  
Café Bienville***

***[www.cafebienville.com](http://www.cafebienville.com)***

***777 John Sims Pkwy***

***Niceville, FL***

***11:30 am – 2:00 pm***

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***Mark your calendar  
for our May meeting:  
Thursday May 23,  
11:30 am - 2:00 pm,  
in Pensacola at  
Sacred Heart  
Hospital. More  
information to  
follow.***

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We were delighted to have Eyvin (Ras) join our group today. His wife Conni attended our February KIT when he was unable to due to an appointment and she was with him today also. Welcoming them were David and Martha, (It was great to see them, and David healthy again), Mary, Larry and Pat, Madge and Roy rounded out our group and Larry brought his brother Bobby who lives in Crestview. We're so fortunate when our employed members can fit our meetings into their busy work schedules. Everyone seemed to enjoy meeting one another and learning a bit about each's myositis type and their coping skills. We hope that Sandra, Doris & Charles and Mac & Sue can make our KIT in February. We miss them. Hopefully we will have some new members also. We stay **Positive that we will grow!**

## **Meeting agenda:**

After some time spent visiting and getting to know each other we talked about the highly successful 25 Year Anniversary Conference in Louisville. Ras & Conni, and Madge & Roy, our members who attended, shared some of their experiences there with the rest of our group. Transcripts from a few sessions and some presentations from individuals on the Medical Advisory Board were handed out to members whose conditions are specific to the topics discussed. Each was also given a complete list of the sessions presented and were encouraged to go to the TMA site to view the videos or read the transcripts of presentations of interest to them. Watching the videos is almost like being there but in some ways even better because you can back up for "instant replay" if you did not hear or understand what was said. That was most helpful to have this ability while creating the handouts for the meeting.

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*We were sorry to learn of the passing of LaShan Davis-Lanier who succumbed to complications from interstitial lung disease November 2. A former KIT leader and amateur photographer, she created commemorative photo books for conference participants and was at the Louisville conference sharing her talents. LaShan will be greatly missed. In lieu of flowers, the family suggests donations to TMA at [www.myositis.org](http://www.myositis.org) or Memorial Fund at [www.gofundme.com/i-n-memory-of-lashan-davislanier](http://www.gofundme.com/i-n-memory-of-lashan-davislanier)*

Most of the handouts dealt with IBM since most of our attendees have that form of Myositis. However, the presentation by Dr. Rohit Aggarwal, MD, MS, and Vice Chair of the TMA Medical Advisory Board has the potential of affecting all of us since it pertains to a study remotely gathering research data from participants over time by way of Fit-Bits, iPhones/Android phones and computers. Dr. Aggarwal believes this innovative approach is going to be a “Game Changer” since access to patients has been a major problem. As this program gets under way it will be promoted by TMA through email and the website so keep a lookout for more to come.

KIT groups were asked to choose a word and create a display that characterized their KIT for their individual table at the Wine and Cheese Reception on Friday evening of the conference. We are a small group but we remain **Positive** we’ll grow, so that was our chosen theme and our display consisted of Newsletters of our previous activities and efforts to increase our numbers. To dress this up a bit, we could not resist the temptation to incorporate our world famous Emerald Coast location into our display with beach scenes, floppy sun hat, sunscreen, flip-flops, sunglasses and a floaty holding a cold beverage. Many observers voiced their appreciation of our efforts. We agreed to meet in Niceville in February and Pensacola in May.

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**\*\*Shingles NEW Shingrix Vaccine\*\***

*Finally, those of us who are immune suppressed can be protected from Shingles!! Believe me, it is worth getting!*

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Please contact me if you have any questions about our KIT, this meeting, TMA, the 2018 TMA Conference, MYO-Connect or any other subject you would like to address regarding our group.

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