



# THE MYOSITIS ASSOCIATION

## KEEP IN TOUCH

### CENTRAL FLORIDA MYOSITIS KIT NEWSLETTER

October 2013 ISSUE

**W**e were very excited to have a record number of attendees at our October 26 Central Florida KIT meeting. In attendance were thirty seven including two speakers. Seven of the attendees were new to our group. We were also fortunate to have had two visitors from the

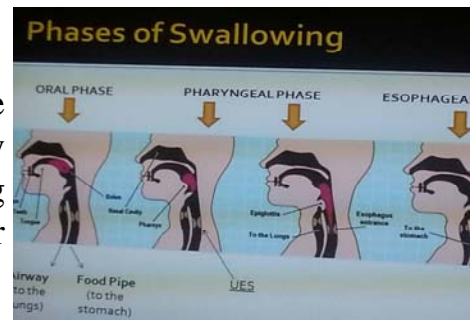


Sarasota group, including TMA's past president of the Board Marianne Moyer.

After some coffee, juice and coffee cake and some good early morning fellowship. We held a short business meeting, with treasures report. After which we went around the room introducing ourselves. We then briefly discussed "The Central Florida Kit Playing Bridge For Myositis." (As of this date the project has raised over \$1800 for research) It is still not to late to go on [www.myositis.org](http://www.myositis.org), scroll to the bottom and click on members campaigns, then scroll down to the bottom and click on the Central Florida Bridge Campaign and follow the directions to participate. All the money will go for research.

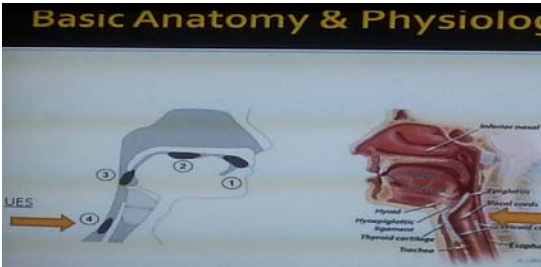
Our speakers were Jessica Wind and her friend and co-worker, Rachel. Both are Medical Speech Language Pathologists who work at the VA Hospital in the Tampa Bay area. They began their presentation with an outstanding Video of the human swallowing process. After the Video they had a power point presentation of a study showing the entire swallowing process. Their talk began with describing how very complicated the process is and a description of all the muscles involved. They then broke down the different phases of swallowing, beginning





with the oral phase; then the Pharyngeal phase; followed by the esophageal phase; and finally the sequence of bolus. They pointed out how our chewing and swallowing muscles including the tongue are very important in steering the food into our esophagus and away from entering our windpipes.

Jessica and Rachel described in detail what dysphasia is, pointing out how swallowing problems are very common. It is most common in IBM, but can cause difficulty, especially in the active or severe phases of PM and DM. Signs and problems to look for is food that is difficult to swallow and causing the sense of choking and a strong desire to cough up the bolus. Usually if food tries to pass into the windpipe a coughing reflex will become very strong. Signs of dysphasia developing are runny nose when eating, watering eyes, and a buildup of phlegm in your throat while lying down at night.



If one is noticing difficulty swallowing it is a good idea to have your doctor prescribe a modified barium swallowing test. While swallowing a some barium, you will be given small amounts of food, bread peanut butter, etc,. Then using a Fluoroscope the speech therapist is able to see where the hang up is and how severe the problem. As a result of this study precautions can be taken to minimize the problem. Smaller bites, liquids along with food, slowing down and looking for foods that you tolerate better can be effective. Throat exercises with some can help as well.

### Myositis: Histopathological Processes

| POLYMYOSITIS & DERMATOMYOSITIS  | INCLUSION BODY MYOSITIS  |
|---|--|
| <ul style="list-style-type: none"> <li>Inflammation</li> <li>Muscle tissue degeneration</li> <li>Progressive muscle weakness</li> <li>Muscle fatigue</li> <li>Muscle tenderness</li> <li>Calcinosis***</li> <li>Lung disease</li> <li>* Associated condition</li> </ul> | <ul style="list-style-type: none"> <li>Inclusion bodies***</li> <li>Muscle atrophy</li> <li>Inflammation</li> <li>Progressive muscle weakness</li> </ul> |

Some patients are referred to a gastroenterologist who can dilate the esophagus, this procedure which has helped many and can be repeated from time to time. Severe cases may have a peg tube inserted to be able to get enough calories into your body to maintain good health. Most of the peg tube users also take in nutrition through their mouths with restrictions of not orally eating the foods that may cause trouble.

### Myositis Types

| POLYMYOSITIS & DERMATOMYOSITIS  | INCLUSION BODY MYOSITIS  |
|---|--|
| <ul style="list-style-type: none"> <li>Women &gt; Men</li> <li>Age of onset: 30-50</li> <li>Trunk affected bilaterally</li> <li>Muscle, connective tissue, and skin affected</li> <li>Skin rash</li> <li>Red flag areas:               <ul style="list-style-type: none"> <li>Neck &amp; Chest</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>Men &gt; Women</li> <li>Age of onset: 50-60</li> <li>Limbs affected first</li> <li>Muscle affected</li> <li>Increased dysphagia incidence = 60-80%</li> <li>Likely a more aggressive process</li> </ul> |

Our speakers were very generous with their time and answered a lot of questions which continued thru our lunch hour. Perhaps one of the best and informative presentations we have ever had.

### Myositis Types & Dysphagia

| POLYMYOSITIS & DERMATOMYOSITIS   | INCLUSION BODY MYOSITIS   |
|--|---|
| <ul style="list-style-type: none"> <li>Swallowing phase most affected = <u>Pharyngeal</u></li> <li>Risks:               <ul style="list-style-type: none"> <li>Reduced efficiency of pharyngeal phase</li> <li>UES dysfunction</li> </ul> </li> <li>Consequences:               <ul style="list-style-type: none"> <li>Increased food/liquid residue in throat</li> <li>Difficult to clear</li> <li>Feeling stuck in throat</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>Swallowing phase(s) most affected:               <ul style="list-style-type: none"> <li>Pharyngeal and Esophageal</li> <li>Oral to a lesser degree</li> </ul> </li> <li>Risks:               <ul style="list-style-type: none"> <li>UES dysfunction</li> <li>Reduced efficiency of pharyngeal phase and esophageal phase</li> </ul> </li> <li>Consequences:               <ul style="list-style-type: none"> <li>Higher risk for airway compromise</li> <li>Not efficient for intake by mouth</li> </ul> </li> </ul> |



For lunch we had catered in chicken sandwiches, chicken nuggets, two kinds of salads. After our lunch break we continued our meeting and talked about the National Patients Conference in Louisville Ky. Marianne Moyer past chairman of the TMA board and one of the KIT leaders at the Southwest KIT group described the meeting from the board's perspective. She told us it was the most attended meeting ever in the ten years since the inception of TMA. She talked briefly about the variety of presenters and the professionalism of the Medical board. Because this year was the tenth anniversary of TMA, a special dinner was held at the Muhammad Ali center for those who wished to participate. The Louisville meeting presenters ran the gamut of very technical to a little softer human side of things. **Marianne brought everyone handouts about next year's conference which will be held in Reno Nevada at the "Peppermill Resort –Spa-Casino. It has 10 restaurants, 15 bars, 2 resort pools and excellent handicapped facilities.** Marianne represents the very best of the TMA organization and always lifts everyone up a notch when she is present.



The conference started on Wednesday with a panel discussion between KIT leaders and the Board of Directors looking for answers to questions pertaining to things that can be done to make TMA stronger and more receptive to the needs of all of us.

One of the items discussed at length was the possibility of getting more direct support from members of the TMA medical board. The good news is that they are willing to help where they can. **An invitation was extended to Dr. Andrew Mammen of the Johns Hopkins Myositis clinic, to attend our Central Florida KIT meeting. We are happy to report that he has agreed to visit one of our future meetings. We are in discussion in trying to work out a date.**

We had a very good discussion regarding the new areas of research going on. New tests being developed to help diagnose the Myositis diseases. Specifically a blood test for IBM and some tests being developed to isolate possible genes that may be causing HIBM. Most of the members that sit on the Medical Board of Advisors were present and presented their area of interest and their research. They answered many questions. Several of them hosted small groups by disease types and were very generous answering everyone's questions. Represented at the meeting were people involved in the new breakthrough research on IBM. Of great interest of course to all with IBM was the Gene therapy trials that have been slowed down a bit due to a change in the testing protocol from the Government. The third IBM patient is going to be injected with a much higher dose in Columbus Ohio.

The Novartis Drug Company, the developer of **BYM 338 (BIMAGRUNAB)**, are going to start a stage 4 human trial with over 240 patients worldwide. As part of the trials Novartis will include 60 patients who will be treated with High dose intravenous infusions, 60 with medium doses, 60 with low doses and 60 with a placebo. Along with this announcement the cities in the United States where the testing will be done have been posted and can get your name on a recruitment list. They are:

Phoenix Arizona, Dr. K Sivakumar 480 314-1007 **Recruiting**

Orange county California Irvine Att. Veronica 714 456-7760 **Not recruiting**

Miami Florida, No location yet or phone number. **Not Recruiting**

University of Kansas Medical Center Dr. Rick Barohn 913 588-6094 Not recruiting

Baltimore MD, **No details, not yet recruiting**

Boston Massachusetts Brigham and Young . Drs. Greenberg and Amato 617 732-8046

**Not yet Recruiting**

Columbus Ohio, Ohio State University. 614 293-4376 **Not yet recruiting**

Portland Oregon **No Information, not yet recruiting,**

Dallas Tex. **No information, not yet recruiting**

This is the information that was given to us in Louisville. If you are interested in participating in the Novartis you need to check the TMA website often. Since this will be a trial that lasts for a year and will require twelve infusions along with follow-ups and muscle tests a couple of times a month, you would need to be near the location. You have to be less than eighty five years of age, and be able to walk thirty feet in six minutes. You are allowed to use a cane or walker. There are some other criteria but these two are the primary ones. The costs of the treatments will be paid for by Novartis. The locations should start recruiting before the end of the year.

Two people who were involved in the early safety trials were present at the National meeting. One of them was given a placebo and the other a low dose one time injection. She was tested several times over several months and the measurements of her muscles showed about a 20% increase in abilities. Since this would be a treatment and not a cure the increase wore off after several months. The drug has been fast tracked by the FDA as it shows so much promise as an IBM treatment.

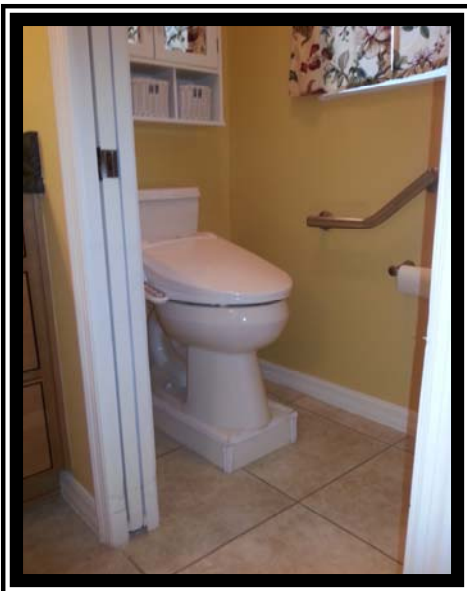
Ed Vick described the conference from the caregiver's perspective. Several of the sessions became quite emotional as the groups reached out to other attendees who had reached the end of their ropes trying to deal with the diseases of their spouses. There were several caregivers' forums and a number of special sessions designed to encourage support for those who give so much to all of us with the diseases. Ed commented on how appreciative he is for the groups support.





Your KIT leaders are already planning future meetings and trying to line up speakers. As mentioned earlier Dr. Andrew Mammen from John's Hopkins has agreed to come from Baltimore and be one of our speakers. As Co-Director of the Myositis Clinic he has a wealth of knowledge in all three of the myositis diseases. We are talking to a Physiatrist a physician who specializes in Rehabilitation. We have considered having a specialist on Assisted living. Another person under our sight is a Physical Therapist who specializes in doing assessments for rehabilitation wheelchair needs. We have suggestions of a massage therapist, and suppliers who do custom designs for handicapped. As soon as we are set on who is coming next we will notify all of you.

### **Modifications to my toilet area.**



I had a 4" high platform built to mount the 17" toilet on. Since I'm in a wheelchair, 5" would have been a better height, because it would have been easier to slide on and off of it. Also, because my hands are not the way they used to be, I installed a very good bidet toilet seat. I'm washed with warm to hot water and hot air dried. This is one of the best investments I made towards this disease.

When I was able to stand, the grab bar shown in the photo was very handy to have. It's angle was helpful as I stood up. If you have questions about it contact me.

Dennis Platt

**Change what you can, forget what you can't.**

**Dennis Platt**

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