



THE MYOSITIS ASSOCIATION

KEEP IN TOUCH

CENTRAL FLORIDA MYOSITIS KIT NEWSLETTER

February 2013 ISSUE

The Central Florida KIT had its fourth meeting on Saturday, Feb. 23, 2013 with 26 attendees plus the speaker. Our KIT started arriving at the South Lake Hospital National Training Center between 9:30 A.M. and 10:00 A.M. for a half hour of get meeting each other. Coffee, soft drinks, water and several cakes were available as the attendees arrived.



At 10:00 A.M. we started the general meeting with everyone introducing themselves. After which we had a short business meeting where we covered the treasurer's report and the dates of future meetings: April 27th, July 6th and October 26th. John Schell talked about a visit he had from one of the financial directors from the Myositis Clinic at Johns Hopkins. She was kind enough to visit while visiting her Grandparents in the Leesburg area. She brought John information on the Statin research being done by Dr. Andy Mamen on the causative links being caused by them and possibly causing other muscle diseases as well. John requested copies of the article that will be sent for us, copies should be available at our next KIT meeting on April 26, 2013.



Dennis Platt Introduced our Guest Speaker— Ferenc Moricz, Assistive Technology Professional, from Active Mobility Innovations.

Ferenc talked about the following:

- **Problems in the industry with getting electric wheelchair approved through Medicare. He then took us through the steps that need to be taken in order to be assured approval, quickly.**
- **Problems with fraud, selling the wrong chair for your needs and false advertising promoting the products.**
- **He demonstrated a rehab chair which he brought with him and showed us the chair's functions that are available to the user.**
- **He spent a lot of time on prevention of bed sores by properly using the different functions of the chair. He also pointed out that by using the reclining function it relieves the pressure on the butt which allows better blood flow to the area.**
- **He pointed out that if you are already having problems with pressure sores then you could qualify you for a higher quality cushion, other wise you would qualify for the next level down.**
- **Having the proper cushions is very important when sitting for long periods.**
- **He showed us and demonstrated the several different kinds of cushions. They included: Basic cushions with layers of foam and gel and several layers of cloth. Air cushions with bladders are used for people who can't move in their chair.**



- **Hybrid Roho with air bladders, foam and hard structure on the bottom.**
- **Fusion Cushions which make you feel you are floating on air have a bladder in them that is filled using an air pump.**
- **Ferenc talked about the importance of choosing the right cushion for your particular need, and the importance of talking to a professional before you spend a lot of money and find that your cushion does not meet your needs.**
- **Cushions come in different widths and depths and should be chosen to fit your need.**



He told us that back cushions were not as important as the seat cushions.

Ferenc brought with him a transfer board which he used to demonstrated how to use it. He also showed us several different kinds of boards and their specific uses.

His closing comments were about car lifts to carry wheelchairs and the fact that most car hitches are not designed to support a chair over 350 lbs. The rehab chairs are too heavy to be carried on the back of a car or van. They require a class four lift which small cars can not accommodate.

At 12:00 noon we broke for a catered lunch brought in from Chick-fil-A. The lunch consisted of their little chicken nuggets, chicken sandwiches cold slaw and carrot salad. Ferenc was able to stay and have lunch with us and answer question from our members.

After lunch and bathroom breaks we had a general discussion with everyone including caregivers present. Usually during the breakout session we get together into the different Myositis groups and caregivers, this time we stayed as one group.

We talked about the following:

- The National Patients Conference in Orlando this past fall. Most the comments were positive and everyone who had attended felt the speakers were informative, approachable, well informed and very willing to answer questions. One of our first time attendees felt they were overwhelmed by the friendliness of all. The only criticism of the conference was the food, especially the sack lunch.

- One of our KIT members brought up the topic of little things we do to cope.
 1. Using a paint can opener to operate power windows in a car or van for those of us who have stiff fingers.
 2. Using a small alligator clip to help pull out the credit card at a bank or teller machine, or at a gas pump.
 3. Using a small ring binder clipped into the hole of zippers to allow a fingers to go into the hole to operate a zipper.
 4. One of the members proposed we all bring to the next meeting at least one gimmick or useful idea that can be useful to enable us to cope.

Mark your calendar the next meeting of the Central Florida KIT will be April 27, 2013. The meeting following this will be on July 6, 2013. The guest speaker will be John J. Scandura, PT, MSPT, OCS, CSCS, Board Certified Physical Therapist, Manager, Rehabilitation Services. The exact topic is still being worked out and more information will follow. It will for the most part be about different exercise that can be used to benefit Myositis patients of all three groups.

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

Dennis Platt