



August 16, 2018

Welcome new members, Kenneth (Mac) and Sue Mcguire joining our group from Pascagoula, MS.



THE MYOSITIS ASSOCIATION

Northwest FL KIT August 2018 Newsletter

A BIG THANK YOU to Sandra for arranging for Kelly (OT) and Carolyn (PT) to join us for lunch and give terrific presentations that can benefit us all. We were also very pleased to welcome two **new members** in *Kenneth (Mac) and Sue Mcguire*, from Pascagoula, MS. We're so glad to have you with us and look forward to a long friendship with you both. Kenneth has IBM and like so many patients has difficulty finding anyone familiar with Myositis, including some doctors. (Thank you, TMA, for working to remedy this problem by sending teams to medical schools to teach medical students about Myositis).

Welcome new and old friends!

It was great to have Larry back with us after his recovery from some medical issues that kept him away for a while. We're so glad that Pat brought him today and that she was able to join us during his absence, to share with us how he was doing and also take news of the meeting back home to him. It was also good to have other faithful members like Doris and Charles and Sandra with us again. In keeping with our goal to KEEP IN TOUCH whether in person, by phone or email, the group was informed of David's being unable to attend this meeting due to a bout of pneumonia. I'm happy to report he is recovering well and has even been back out for a bike ride and to his gym for his regular workouts. Way to go Larry and David! Keep those POSITIVE attitudes. We hope to see you both, along with Pat and Martha, at our November 15th meeting and perhaps in Louisville. We also want to keep in our thoughts and prayers Regina and her husband Jerry in Panama City as they battle his cancer and her DM and recovery from a rotator cuff injury. Even though you can't attend our meetings, know that we are thinking of you and wishing you well.

Meeting agenda:

Mark your calendar for our next meeting: Thursday the 15th of November, 11:30 a.m., location to be determined. More information to follow.

Kelly, OT – can be reached at:
Kellydunn@yahoo.com
 Or 850-637-4288

Carolyn, PT – can be reached at:
cdwarnold@gmail.com
 or 850-313-6531

We began by welcoming Mac and Sue as new members of our group and applauded them for driving from Pascagoula. (The timing must be right to “make it through” the tunnel in Mobile ☐.) Mac said he was so glad to receive an email from us advising of the meeting since finding anyone familiar with Myositis had been a real chore. He appreciated discussing with Larry and Sandra their respective experiences with IBM, finally having something to compare with his own. After thanking Sandra for them being there, Kelly and Carolyn were introduced and took turns with their presentations while the other enjoyed lunch with us.

Kelly began with a brief description of her credentials and the company they work for, *Kindred at Home*, www.kindredathome.com in Pensacola. Both she and Carolyn looked far too young to possess the years of experience they both do but their presentations certainly proved their skills. Their company offers Nursing, Physical Therapy, Occupational Therapy, Speech Therapy, Medical Social Work and Home Health Aide. For more information or to make a referral, call 850-434-8662. Their office is located in Pensacola. Kelly works with hands and her main goal is to assist patients recovering from injury to regain life skills and provide support for adults struggling with activities of daily living, such as dressing and eating including:

- *Specific musculoskeletal disorders*
- *Fine motor skills*
- *Adaptive equipment (DME) and home modification*
- *Low Vision Therapy*
- *Help in regaining ability to perform Activities of Daily Living (ADL) including retraining in dressing, cooking, bathing, toileting etc.*

*Don't forget the
2018 TMA
Conference in
Louisville
September 6 – 9
Celebrating The
Myositis
Association's
25th Anniversary!!

Some sessionss
may be available
live or shortly
after they are
presented.*

*Go to:
www.Myositis.org*

Kelly brought several items that aide in feeding and dressing and demonstrated how each worked. She said they were available from medical supply businesses such as Grace Durable Medical Supply on 9th Ave. in Pensacola. And many are available from Amazon. She illustrated how some home utensils can be modified with foam tubing available from Home Depot. For those having difficulty closing their hands around such items, the handles can be made easier to grasp by covering with the tubing. The size about the circumference of a 50 cent piece, with an inner hole about the size of a dime can be cut and slipped onto eating utensils, cooking utensils (Not pot or pan handles that are HOT!) and brushes etc. Kelly's presentation was GREAT!

****See last page for photos of some items in her presentation.****

Carolyn began her presentation with a brief description of her experience and explained that as a physical therapist her concentration is on rehabilitation for larger muscles, Balance, Lifts, Slide Boards and alternate ways for doing things to maintain independence. There are five considerations to achieve balance:

1. Eyes
2. Inner Ear Sensors – are you moving?
3. Strength of the Lower Body
4. Feet – Type of Surface you are on
5. Brain – Are you moving or not?

She advised, ***Caution while turning*** “When you find yourself *Furniture Surfing*, by holding on to walls and furniture to move around your home or falling backward when you look up over your head, it is time to seek help in strengthening muscles to improve balance and allow you to turn your head while walking. There are isolation balance services that target specific issues. Without therapy, these conditions usually get worse.” These therapies can **help** even if you are not able to progress from a walker to a cane. She urges that requests be made to our physicians for referrals for therapy for **BALANCE!** “Work for the **SAFEST MOBILITY.**”

She closed by warning against using inappropriate substitute shower stools when more stable ones are available and described some new motorized chairs that tilt and recline: The back, legs and seat adjust independently or together to lie flat. For those finding they need to

begin using a walker or wheel chair, the Easter Seals Goodwill in Pace, FL on highway 90 will GIVE medical items such as these and have all types come through their facility. Give them a call, leave your name and phone number to arrange pick-up of these items.

Both these presentations were so helpful and informative and we are very appreciative for all we learned from Kelly and Carolyn.



We had a brief “business” meeting deciding on a date for our November meeting and offers were made for volunteers to plan a program, write the newsletter, publicize our meetings (or *become the new leader?* □ They’ll get back to me. □) We closed at about 2:15 and wished all good travels home, especially Mac and Sue through the Mobile tunnel. Hopefully they missed the evening “rush hour.”



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

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

You should get Shingrix even if in the past you:

- *Had shingles
- *Received Zostavax
- *Are not sure if you had chickenpox

Many private health insurance plans and Medicare Part D cover shingles vaccine, but there may be a cost to you depending on your plan.



Special events will occur at the Annual Patient Conference in Louisville, September 6th – 9th, and there will be some ways for you to help TMA and help yourself in Celebration of the 25 years. There will also be some activities that are just purely for fun! See you there!



THANK YOU to TMA Medical Advisory Board our HEROS!

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.

Madge Chambers, leader

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Items demonstrated by Kelly:



Rocking knife (like Alaskan Ulu) helps cutting meats etc.

Knife comes with the protective sheath.



Adapted knife, fork and spoon for easier grip



Button hook/Zipper pull (only one hook on left end; lower is a shadow)

Continued items demonstrated by Kelly:



Universal cuff with slide-in slot for utensils



Reverse of Universal cuff above

Other helpful items to search for: Nosey Cup, depression on top edge allowing space for nose; Ergo Rests for arms; Dycem non-skid mat to hold dishes and pots in place without holding; Elastic shoe laces – turns all shoes to “loafers”; Universal shower chair.