

NWF Panhandle KIT Newsletter

December 2016

Our fledgling NWFL Panhandle KIT met in Niceville for its organizational meeting at 11 AM November 17, 2016. Three of our members who had planned to attend were unable to due to medical issues but we still had nine members and caregivers in attendance. Hopefully those three will be healthy and able to join us next time along with some new members. We had three IBM and one PM member present.

Topics Discussed

After a meet and greet social period, we sat down to a light lunch and discussions about our respective stories of living with Myositis. Larry and his wife explained he has a "lift recliner" for his "at home" chair and two portable lift devices, one manual the other electric, which can be taken on outings. And he has portable ramps to aid in wheeling over obstacles such as doorways. He uses an electric toothbrush, zipper ties, and foam covers on the handles of his eating utensils. They also described some clothing they found adapted with Velcro fasteners in lieu of buttons and zippers making it easier to dress without assistance. Larry says he is aware of several Veterans at the VA clinic in Pensacola that have Myositis. We will try to get information about TMA and our KIT placed there!

David brought some items that have helped him maintain independence in performing daily tasks. These include a Button hook device to assist with buttoning; foam tubing, like Larry's, with a hollow center slipped over a pen, razor, cooking and eating utensils making the handles larger and easier to grasp. Also he showed two types of stretchable shoelaces that eliminate tying and demonstrated how rings (found on valet and auto service tags or even key rings) can be fed through the hole in a zipper tab to make it easier to grasp and zip. Another aid for zippers is narrow leather pulls; even a short length of cord tied through the hole in the zipper tab works. There are gloves available with Velcro straps that wrap around the hand to strengthen grip for working with household and gardening tools and athletic equipment like a fishing rod. He still operates a small business involving deliveries and discovered the new push-button starters on autos eliminates the need to turn keys and motion sensors will open the hatch when a foot is placed under the rear bumper. Another great aid to him is the Wi-Fi in his car enabling him to use his phone for calls and directions without taking his hands from the wheel. His strong advice...."the next time you are making a major buying decision, make sure you know all the helpful gadgets out there to help you keep your life functional." He mentioned the status of the Follistatin gene therapy clinical trial he is participating in and he and Boyd shared how daunting to realize how long and expensive it is to get new drugs to market, IF proven effective. Our very rare disease doesn't provide a large market for drug sales so drugs coming available for major diseases like Alzheimers may be a better route to treatment and perhaps a cure. He suggests IBM patients check www.clinicaltrials.gov for a new Alzheimers trial about to start in Kansas City using IBM patients for research.

Other topics discussed

Since we are widespread (Pensacola to Tallahassee = 196 miles), after a brief discussion, our plan is to meet quarterly and vary the location to allow greater access to potential speakers and programs and to prevent the same members from having to travel the long distances each meeting time. We are tentatively planning our next meeting for February, date and location to be determined.

Drawing in new members is a priority. Dee met an interested prospect while on a lab visit the other day so we will not be discouraged. Unfortunately we received only one response from the eight additional TMA members contacted from the FL list provided by Charlia, but I will try again and request the AL list to search for those members close to us. We decided to request more TMA posters with tear-off slips for TMA and to attach cards with contact information specifically for our KIT for easy access. These will be distributed by each member in their respective areas. We agreed to work together to get the word out about TMA and our KIT. We are excited about our group finally materializing and encourage all interested individuals within our geographical area, including south Alabama, who have Myositis or family members with the disease to contact us at: NWFTMAKIT@cox.net or mepc65@icloud.com. Madge Chambers, KIT Leader

Aids in daily living products are available on these websites:

Pattersonmedical.com WrightStuff.biz Mobility-Aids.com ActivenAble.com

CareGiverProducts.com ArthritisSupplies.com GoldViolin.com

epic-id.com – (USB Emergency ID – information available to EMT/Police to access via their on-board computers)

Have a very Merry Christmas, Happy Holidays and Healthy New Year!

Please join us at our next meeting in February. More information to come.