



THE MYOSITIS ASSOCIATION

KEEP IN TOUCH

CENTRAL FLORIDA MYOSITIS KIT NEWSLETTER

January 2014 ISSUE

Our January 2014 Central Florida TMA KIT meeting started off with a bit of a sugar high as all twenty of us, it seems, brought a coffee cake to go along with our early bird Coffee, Juice and fruit. After about a half hour of eating and greeting, we settled down to a little KIT business. John Schells' wife Sherry announced that her first effort to raise money for TMA by sponsoring the "Annual Royal Highlands Central Florida/KIT Bridge Tournament has raised to date close to \$2000 for TMA. Sherry's neighbors along with other contributors from our KIT have been most generous. After a few more announcements we introduced our speakers.



We were very happy to have for this meeting, **Kathy Haviland**, Founder/CEO and president of the "Tri County Senior Outreach Services." It is an organization dedicated to providing care to elderly and disabled. Kathy recognized the difficulty of accessing services needed by senior or disabled individuals, without professional guidance and a care plan for implementing them. For example, where do we start or what do we do if our "Care Partner" has to go out of town for a family emergency? Accessing something seemingly simple like where can I get five day respite care without having to make lots of phone calls. It would be easier to have



one person to contact. Where can I find help to facilitate my care partner getting in and out of the shower? To this end Kathy is the person who will meet with you and assist you in putting together a care plan. She maintains associations with financial planners, nursing homes, assisted living facilities, Hospice organizations and skilled nursing in home care resources. Kathy does charge a small fee for her services, the amount being determined by the extent of the services. Kathy brought with her a team from several of the areas she talked about and each of them made presentations to us regarding what they can offer to us. Kathy is the one that can use her experience to put together a coordinated care plan. She can be reached at:

tricountyoutreach@gmail.com

352 551-1260

Our next presenter was **Mr. Scott Keiber**, Financial and Estate Advisor. His first question to us was when is the last time you looked at your wills or trusts to make sure everything is in compliance with your wishes? Are there any additions or corrections that may need to be incorporated due to births, deaths, or divorces? Are you current with those named as guardians, trustees, executors? Are those named as beneficiaries in line with your current wishes? Are your health



care directives, living wills etc in compliance with the laws of the states where you now reside? If you have questions regarding any aspect of estate planning including financial planning or any other legal matters. He can be contacted at:

scott@retirement.com

352 404-5158 Clermont

407 616-7000 Orlando

877 869-9848 Toll Free



Our next speaker was **Cauline Gillespie**. She has been a RN for 30 years and represents Phoenix Home care. They are a Medicare certified service. They provide in home PT, OT, speech therapy, Lymphedema Therapy, Anodyne Therapy, Vestibular Therapy and home health aide Social services. In addition they provide skilled nursing for COPD, CHF, Diabetes Stroke / CVA and other health conditions that affect the person being unable to leave their homes without considerable risk. Cauline can be contacted at:

www.phoenixhomecareinc.com

352 242-1005

Laura, a representative from **CSI Caregiver Services**, talked about in home care including meal preparation, light housekeeping, companionship, bathing and personal hygiene care, along with more skilled in home care needs. They have 18 local offices scattered throughout Florida. They can be reached at:

www.csicaregiver.com

352 245-4473

Arbor Village of Wildwood was represented. They provide skilled nursing care and in house rehabilitation. They can accommodate respite care as well and try to take an individual person-directed approach to all their residents. They can be reached at:

www.arbor-village.com

352 748-3322

Our final guest was Hope Hubbard representing Cornerstone Hospice and Palliative Care. She made a wonderful presentation stressing that hospice is not a place you go to die in a few days. Instead it provides all sorts of benefits that can affect the life of an individual while they are still able to live a full life and enjoy it in their home environment. Medicare pays for medication and for 5 days of Hospice house care. This is not a topic most of us want to talk about, but it is wonderful to know they are there if we need them. Hope can be reached at:

hhubbard@cshospice.org

352 360-3579

Remember in order for any service to work for you it is necessary to have a coordinated plan with the right people in place. We are very grateful to Kathy Haviland for putting together this very full and interesting presentation. If she can do it for a KIT just imagine what she can do for us individually if we need help.

Kathy Haviland

352 551-1260

After our catered lunch and a little catching up we settled into a discussion about what we do to make our life easier around the house, in the car, or whatever we are doing. We talked about exercise, exercise machines, portable bidets, and how to brush your teeth from a wheelchair.

Chris Parsons told us about a product he has purchased called **MOTomed**. It allows him to sit in his wheelchair and exercise his legs with passive power assisted movement therapy. <http://www.motomed.com/en.html>

Robert Hazelet showed us a very clever device called a Sanicare Power Bidet. It fits in the back of his wheelchair and he carries it with him. <http://www.sanicare.com/Sanicare-Travel-Bidet-Portable-Bidet-p/tbo.htm> Bob also showed us some sticky little tabs which affix to the edge of his credit cards and allows him to pull the cards out of his billfold and out of card readers ATM's etc. They are called **Yank Tabs**. www.yankatab.com

If any of you need a wheelchair, power toilet, or any other adaptive device. We keep a list of what others are desiring to sell. Contact John Schell schelljh37@comcast.net 352 314-8953

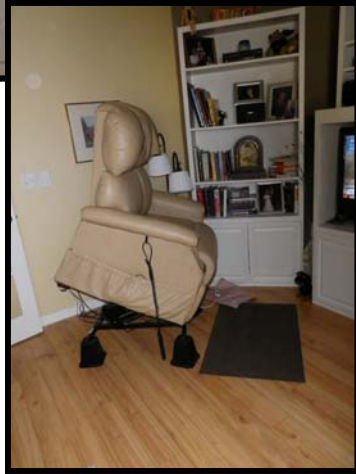
We have a lot of people on our email list. Some of you we have never met and would love to have you attend one of our meetings. We are a good, fun and active group and would love to have you attend. We are always looking for speakers and speaker ideas. We would appreciate any ideas any of you have to improve our KIT, or to improve our communications with you. If you are a person who is unable to attend because of lack of transportation let us know. We might be able to help.

John Schell started the discussion by talking about his quest to have a accessible bathroom including a vanity that doesn't look like a motel room with open plumbing.

He actually had a neighbor come in and design a vanity with drawers and an opening that allowed his wheelchair to get him up to the sink. The designer even custom fitted the drawers around sinks and plumbing to allow for maximum use of space. John also talked about the importance of grab bars in areas where he needs to stand and pivot or bear some weight. On either side of his lift toilet he has affixed grab bars so he can pull in with his wheelchair, lift to a standing position, turn and sit. **See pictures**



See you all in April,
John, Dennis and Kevin



Our next meeting will be **April 26, 2014**

Change what you can, forget what you can't.
Dennis Platt
dennis32162@gmail.com