



THE MYOSITIS ASSOCIATION

KEEP IN TOUCH

CENTRAL FLORIDA MYOSITIS KIT NEWSLETTER

April 2014 ISSUE

There have been are many interesting things happening and we wanted to include everything about this meeting along with announcements of coming events.

After our meet and greet of twenty participants and enjoying a little coffee, fruit and home-made coffee cake, we began our meeting. Everyone introduce themselves while our speakers set up the AV equipment. Sherry Schell gave the treasurers report which showed we had a balance of \$216.09 after all expenses were paid.



People who have diseases that keep them inactive by being in wheelchairs or sitting a lot often develop swelling in our feet, ankles and lower legs. The condition is called Lymphadema. It is caused because the lymphatic system which drains fluids back into our circulatory system does not work properly. If Left untreated it can cause ulcers on our feet and ankles. Another problem we all face is loss of core strength by disuse.

Our guest speakers addressed both of these problems. Meenu Jethwani is owner of three Physical Therapy businesses. Two are in Ocala and one is in The Villages. They specialize in treating Lymphedema. Meenu is a licensed and certified occupational therapist with specialized training in Lymph edema massage and therapy.

Most doctors prescribe water pills for swelling in lower legs along with pressure stockings. The problem that most of us have with that, especially those of us with weak fingers, is that we

can't get the stockings on. Meenu's approach is to first get the fluid out of the lower legs by the combination of pressure wraps and then a specialized massage to move the fluids back into our circulatory system. John Schell just finished several weeks of going to their office for the wrapping and unwrapping and massaging of the legs. This was covered by his Medicare. Then instead of pressure hose and water pills they use a self-massage technique taught to you and leg wraps you can take on and off easily. Meenu showed a chart of the lymphatic system and explained the importance of it to our health.

Our next speaker was Geoff, he talked about the importance of balance. He said that it can be practiced at home by holding on to a grab bar or walker while picking up one foot and trying to stand on the other one. Posture while sitting is very important to maintain good core strength as is sitting exercises of the shoulders and hips. Stretching one arm with the other arm in one direction while looking in the other direction, this helps keep your trunk muscles strong. Another good exercise is sitting in a chair with your head down with hands out in front of you and then rotating left and right, this also builds strength. To help keep you independent seek out OT devices like page turners, doorknob pads and other items that.

We really appreciated their presentation and taking a Saturday to spend it with us.

If you are having a problem in this area Meenu can be contacted at www.lymphedemaclinic.net or 352 391-9500

As usual we had a catered in lunch and then were treated to a special treat when two of our own, Tom and Joann Smith, shared their experience with Tom's stem cell transplant while in Phoenix.

www.PhoenixStemCellTreatmentCenter.com if you want to check it out.

They described the procedure by explaining how Tom's stem cells are taken from his own belly fat by a liposuction technique. Fatty tissue is loaded with stem cells. They are then processed while you wait, then put back into your own body. Some were injected directly into his affected areas like Quads, Arms, etc., and the rest were put back into his system through an IV. The treatment took about five hours in total. Since this procedure is considered patient personal research it is paid for by the patient, which cost them about \$9,000. Since nothing is being injected into your body except your own stem cells the risk is minimal and not regulated by the government. Tom reported very little discomfort and no side effects.



By this time the entire room was silent waiting to hear what happened. I think Joann com-

mented first as she rubbed her fingers thru his newly growing hair. We all laughed about that one. Then she commented that all the dry itchy moles on his back started sloughing off. On a more serious note Tom demonstrated how he was able again to lift both of his hands and arms straight up. As his arms grow in strength he is better able to push himself up off his wheelchair and walk with his walker again around his house. He is also able to lift his feet off his wheelchair by himself, get out of bed by himself with the help of a grab bar, by his bed, and step into his shower again by himself. Joann reported that he is much more independent then he was. These are big things! Anything we get back that enables us to assist ourselves and take a little pressure off our care partners is a huge step forward and worth looking into.

By the time Tom finished John Schell was ready to drive to Phoenix. He contacted them, and was sent an application, which he filled out and sent back. While waiting for a response back he started checking for places closer to home to get it done. He found several stem cell centers



that take bone marrow and growing stem cells but that procedure takes a lot more money. He then found the **TheMiamiStemCellTreatmentCenter; Dr.Nia@MiamiStemCelsusa.com**

You can also contact their executive assistant Nicole@miamistemcellsusa.com; 561 419-3004. Same price, same procedures. John Schell is schedule for the procedure in Boca Raton on June 23. A lot easier then going to Phoenix.

We will be privileged to have Dr. Nia Smyrmiotis, Medical director of the Miami Stem Cell Research and Treatment Center, be our speaker at the JULY 26th KIT meeting in Clermont.

She will be able to answer any questions you may have on this subject. Dr. Nia is also an affiliate of the Irvine Stem Cell Treatment Center and California Stem Cell treatment Center and cell Surgical Network. She is also Professor of Biomedical Sciences and Human Physiology, and Chairwoman, Department of Integrative Medicine American University of Sovereign Nations School of Medicine. She is a graduate of Indiana University with a Bachelor of Science in both Chemistry and Biology and has a medical degree from Chicago Medical School. Along with these qualifications she has specialized training in Stem Cells procedures, protocols and procedures.

Because of the huge interest in this new area of research, we would like to open our Central Florida KIT to the Jacksonville KIT and the Southwest Florida KIT.

Some of you who don't normally attend a KIT meeting may want to attend this one as it will be very interesting. Dr. Nia is qualified to answer all of your questions. This does have application to PM and DM as well

If you plan to attend this meeting contact john Schell at: schelljh37@comcast.net

John, Dennis and Kevin

Our next meeting will be July 26, 2014