



**THE MYOSITIS ASSOCIATION**  
*KEEP IN TOUCH*

**CENTRAL FLORIDA MYOSITIS KIT NEWSLETTER**

**July 2014 ISSUE**



Article written by John Schell

**H**ello everyone. All of us who are involved in the leadership of the KIT were thrilled to have forty people attend this meeting in the middle of July when so many are away.

As usual the meeting started out with rolls and coffee for the early birds, followed by a meet and greet, a few announcements and an introduction of some special of out of town guests. We are very lucky in Florida to have such a strong representation of KITs. Marianne Moyer, past chairperson of the Myositis Board attended from the Sarasota KIT along with her husband John; Rose and Mat; Barb Kluding and Patches, from the Sarasota KIT. Also attending from South Carolina were Dannie Haines, retired board member and her husband Howard. It was wonderful to see Chris and Laura Parsons as well.



Dr. Nia Smyrnriotis

Our speakers for this meeting were two very well qualified Dr's from the Miami Stem Cell Treatment Center; Thomas A Gionis, MD, JD, MPH, MBA, MHA, LLKM, FAIHQ, who is a fellow in "the American Institute for Health Quality" and Nia Smyrnriotis, MD, MS. Dr. Nia has completed training in stem cell procedures, protocols, and treatment.



Dr. Thomas A Gionis

Stem Cell Therapy has been around for a number of years and is certainly not without critics. It is permitted by the FDA to treat various conditions including neurological conditions, spinal conditions, cardiac conditions, orthopedic and auto immune diseases. There is much research going on around the world including several labs at the NIH.

Dr. Gionis and Dr. Nia spoke for over an hour and a half on different types of stem cells and procedures. One way is from bone marrow, which is painful and usually very expensive. These stem cells are then grown in a lab dish. Most of these procedures are done in research labs. Other types of stem cells can come from fetal umbilical cords, grown in a lab and then inserted into another patient. There have been problems with these because they can carry genetic markers from the donors including other diseases. Injections of the stem cells that are processed this way have to be done outside the United States.



Stem cells are found throughout our bodies in varying quantities. The type of cells we talked about at this meeting are called “ADIPOSE DERIVED STEM CELLS.” These cells are harvested from belly fat which contains very high numbers (in the millions) of them. This type of cell has the ability to change into other types of needed cells; i.e. neural cells, blood cells, cardiac, muscles, etc. The purpose of stem cells is to perform rescue missions to repair damaged parts of your body.

The steps for stem cell therapy are as follows:

1. A consultation is held to determine if you are a candidate for the procedure. If you have an active cancer you most likely would be turned down. During this phase you are free to ask questions and your medical records are ordered. No promises will be made as to cures; implied or otherwise. The stem cell procedure is considered non empirical research and is paid for by the patient.
2. When the procedure is done you will be given a local anesthesia under sterile conditions.
3. A very small incision will be made into your love handles using a mini liposuction technique. It will take about twenty minutes.
4. The stem cells are isolated and separated from the fat cells; and
5. Finally, the stem cells will be reintroduced back into you own system ether by injection or thru an IV drip. At this point timing is very important. Everything must be done within a set time frame.

During the presentation we were shown slides of body tissue that had been treated with this method of adipose transfer; heart, lungs etc. This clearly showed that new tissue has grown in those cases. The question then becomes will this procedure work for forms of myositis? The answer to that question is, we don't know yet! That is precisely why some of us are subjecting

ourselves to this procedure. It is good science. It could be considered expensive, and, at this juncture of time, cannot be measured by empirical research.

The presentation by the Doctors was interesting, honest, and very professionally done. After lunch, four of us who had the procedures done answered questions from attendees. Did it work? Dannie Haines told us how she is again able to breathe better at night, to swallow foods again without her feeding tube. John Schell has gained more strength in his legs to again shower himself and get up from a shower chair without help. John is participating in PT and has added upper body strength to a point where he can push up to his feet from a



wheelchair by pushing on parallel bars. John is also walking twenty lengths of a swimming pool (20 yard lengths) up from only four. Tom Smith reports being able to lift his arms off of his wheelchair arms to an overhead position and hold them up. Bob Marques for the first time in several years is back exercising in water. I would urge everyone who has had stem cell therapy to report back all results good and bad to our KIT. I think it is important to be absolutely honest about the experience in order to properly evaluate where the science is. For sure it is not junk science as some would have us believe. The question is whether or not it will work for myositis as well as we hoped it will.

Since our meeting there has been several more people treated, and are we are waiting to see the improvements they get. I can only speak for myself, but would make this statement; I have more energy. I am exercising again and seem to have more strength. I can again do things I was unable to do before. Would I do it again? Yes, but only if I could afford to lose the money. Otherwise I would wait for more reports.

The rest of the afternoon was spent discussing KIT business, the National patient's conference and the National Myositis awareness day that was just held.



Thanks to Tom Smith and Dennis Platt in the Villages, TMA received a wonderful full page article in the Villages' Daily Sun. This newspaper has coverage throughout the entire Central Florida. As a result our KIT has received numerous phone calls by people wanting to know more about TMA, our KIT support group meetings. In addition they wanted more information on Myositis in general. TMA has been very generous with information about Myositis which will be available to hand out to our physicians. We will have a supply at our next KIT meeting on OCT 25, 2014.

More information and this month's agenda will follow soon. We are going to have a wonderful speaker. Please try to attend.

At our past meeting we talked about Sherry Shells Myositis for Bridge/Central Florida KIT fundraiser. Several of you last year contributed even though you did not play bridge. All the money will go for Myositis research. Donations can be made directly to “The Myositis Association” by going to [www.myositisassociation.org](http://www.myositisassociation.org) and then scrolling down to member campaigns, to ours. You can also send Sherry a check made out to “The myositis Association” and we will send it in for you. If you live in the area of Leesburg and want to play just let Sherry know. The event will be Friday Oct 17th.

**BRIDGE FOR MYOSITIS**

Friday, October 17, 2014 1pm-4:30 pm

Recreation center card room

Party Bridge and Sanctioned Duplicate Bridge

We're hosting a bridge game to raise money for Myositis general research. Myositis is a debilitating muscular disease. The cost to enter will be \$5.00 (or donate more) Bring your own partners! Sign-up sheet is in Reek Center.

For information call  
Sherry Schell 314-8953  
Bill Fleischman 459-0311

Donations can be made by checks made out to The Myositis Association or donated directly to the Myositis Association by logging onto [www.myositis.org](http://www.myositis.org) and scrolling down to member campaigns, Sherry Schell/Central Florida KIT. \$5.00 entry will only be collected from bridge players at the door.

If anyone has done a project to makes life easier for themselves, send me pictures and I will share it with everyone. Also, if you are finding it difficult doing something, let me know. I'm sure there is someone in our group who has found an easy way to do it. We all have the same problems, its just how we handle them that counts.

**The 2015 Annual Patient Conference** is scheduled for **September 10-13 in Orlando, FL.** The Conference will be at the Caribe Royale, the same hotel we used for the Conference in 2012. The Caribe was very well suited for the special needs of myositis patients and was rated very favorably by those who attended. Sleeping rooms at the Caribe are available for \$109 and can be reserved by telling the reservations desk that you are attending The Myositis Association Annual Patient Conference. Reservations can be made at the Caribe by calling 1-888-258-7501.

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