

Mid-American Myositis KIT

Hello Again

Our KIT (Keep In Touch) group was successfully launched on January 19th, 2013 with 15 people in attendance from Kansas and Oklahoma .

After routine introductions of all attendees, great discussions filled the next two hours that included individual conditions to helpful tools used every day.

Frequency of meetings was discussed with the majority of attendees agreeing that 3 times a year would be appropriate. The next meeting date recommended was May 4, 2013. (Mark your calendars)!



15 people attended the 1st Mid-America Myositis Kit meeting

Myositis Ribbon Magnets were awarded to the person traveling the farthest, the person diagnosed the earliest and the last diagnosed.



Myositis discussion between members from Oklahoma & Kansas.

We have a Sponsor!

The fine folks at **Stand-Aid of Iowa** are our KIT group's sponsor for this quarter.

Stand-Aid is a regular sponsor seen at the last three TMA Myositis conferences. We appreciate their involvement with our KIT group. Their sponsorship is necessary to

offset the refreshment and snack costs incurred at meetings, any mailings, etc. Make sure to visit their website at www.stand-aid.com. Also reference their ad later in this newsletter. Please feel free to call them anytime about their product offerings.

Favorite Tools

When you get to the discouraging point that your myositis hands and fingers find it difficult to button and zip your pants, the first thought is to get some bottom wear with elastic and without the zipper & button/snap. Going out and buying a new wardrobe can be expensive, but that spending can be delayed if you invest in a Pocket Dresser. A Pocket Dresser is a pocket or purse tool that features four tools to assist you:

- Large pants button tool
- Small button tool
- Zipper puller
- Shirt button tool

This tool is a heavy duty replacement for the

inexpensive aids that claim to do the same tasks.

Available on-line for anywhere between \$28 & \$59. The one pictured above was purchased for \$28 from Active-Living.com (item DL1217), about a year ago and is used many times a day.



Pocket Dresser

The aircraft aluminum case and stainless steel tools should last a lifetime. Reclaim your already owned wardrobe with this tool.

If you have a favorite item or tool that you use to make your day a little easier, email the information to mid_am_myositis@aol.com for insertion into a future edition of this newsletter.

Eating An Anti- Inflammatory Diet

Positive Effects of Anti-Inflammatory Diet In a study,

Rose Mary Istre & Kimberly Wilhoit found those with myositis who followed an Anti-Inflammatory Diet over 12 weeks had improved:

- Ease of routine activities
 - Severity of depression
 - Grip, arm, leg strength measurements
- Avoid processed foods: eat “whole foods”, the way nature intended it .
- Avoid sugar, high-fructose corn syrup
- Eat lean protein, more fish and whole soy products, less animal protein

Other Anti-inflammatory Eating Tips:

- Eat only Pacific/Alaskan wildcaught Salmon; all other types of salmon are farmed and have higher fat contents

which is where toxins like mercury are stored.

- No bottom feeding fish
- Dairy is neutral
- Eggs are ok, but should be natural, free run and grain fed
- Cold cereals, too much sugar, added nutrients not good
- Rice milk is better than soy--soy can present problems for cancer patients especially breast cancer
- Alcohol: red dry wines are lowest in sugar but higher in antioxidant qualities
- No instant oatmeal only whole grain oatmeal
- Olive oil is very good if you are going to use oils
- Frozen wild blueberries by Tiff or Dole are very high in antioxidants
- Avoid grapes because of the sugar content
- Make non roasted trail mix
- Non-roasted nuts, choose those lower fat varieties
- Minimize dried fruits because of the high sugar content
- Look at the high antioxidant juice ingredients and avoid those that have multiple ingredients
- Avoid regular fruit juices in general
- Multi grain whole grain breads, not just whole wheat bread

- Be careful with fresh raw veggies during flu season because they are handled by many people
- White potatoes are not recommended, sweet potatoes are better
- Turmeric and cinnamon are very good antioxidants
- Tomatoes are great, even cooked (olive oil with tomatoes is a very good combo; the olive oil helps the absorption of the lycopenes)
- Dark chocolate with low sugar content (cocoa nibs has no sugar, but high in antioxidants)
- Use honey minimally
- Pomegranate juice is very good!
- Sweeten your tea with pomegranate juice
- Cheese is pretty neutral
- Use yogurts that have no added sugars and mix in your own fruits or nuts
- Use flaxseed **meal**, not the whole seeds

Studies show it is better nutritionally to eat real antioxidant and Omega foods over and above relying on Supplements.

Connect with TMA

The Myositis Association (TMA) is a recognized leader in promoting all causes for myositis. TMA is a major part of your KIT group and continues to help by providing support to myositis patients and families. TMA does not charge a fee to belong to its organization, but you can easily support their financial needs by using “Goodsearch” as your internet browser. Goodsearch donates one cent to TMA for every internet search it is asked to perform. Additionally, if you utilize their “GoodShop” or “GoodDining” feature, the vendors that you purchase items or food from will donate between 1 and 6% of the purchase price to TMA. TMA use these funds to promote clinical research and development of myositis treatments.

To change your internet browser to utilize GoodSearch, click on Tools, then Internet Options and enter www.goodsearch.com in the Home Page tab. Enter “The

Myositis Association” in the group you would like to support and press enter. Fill in any info required to register TMA as your fund to be donated to. When you want to use the GoodShop feature, check the list of the many companies and stores that offer a percentage of your purchase to TMA at no extra cost to you. You can even search for special savings coupons to be used towards your purchase. If we could get 10,000 people to use GoodSearch and accumulate only \$10.00 each, that would be a donation to TMA of \$100,000 that would be used in combating myositis. Tell your friends and ask them to support your cause also.

2013 Conference

TMA's 2013 Annual Patient Conference will take place in Louisville, KY from October 17-20. The Conference will be held at the Marriott Downtown and rooms are now available at the TMA group rate of \$109/night. To have the best chance of getting the type of room that you would like, we encourage you to reserve

your hotel room early. For reservations, call the Marriott Downtown at (502) 627-5045 and inform them that you are attending The Myositis Association Annual Patient Conference. We had 350 patients and their caregivers attend each of the Annual Patient Conferences the last two years and expect to have at least that many next year in Louisville. Conference activities get underway midday on Thursday, October 17, and the Conference concludes Sunday morning, October 20, around 11:30 am

Are CFL Bulbs good for Myositis?

A few years ago, our government imposed a mandate towards the conversion to compact florescent lamps (CFL). As there are many energy savings affects that help us, were the negative aspects of CFLs fully investigated

before the mandate was imposed? Maybe not!

There now seems to be a lot of interest and investigation that the CFLs that emit ultraviolet rays, may result in triggering certain, and many different types of disease.

Any disease that is considered in the autoimmune category, could be worsened by the effects of ultraviolet lighting.

CFLs share the characteristic of producing light in a spiked spectral pattern, with low illumination between spikes. This 'spiked' spectral pattern is associated with stimulation of the red-blue pupillary flicker response. People subject to this response report various neurological effects ranging from drowsiness to migraines.

There is little or nothing on the CFL labeling that states anything about health risks, and the government has not informed doctors that patients with lupus or autoimmune diseases should be told about the risks.

Since myositis patients have been told to avoid a lot of UV

emitted by the sun while taking certain medicines, should we also take heed to the discussion about the hazards of UV from CFL bulbs?

New Email Address

Future Mid-America Myositis KIT correspondence being sent to your email box will be sent under the new email address of mid_am_myositis@aol.com.

We feel that this address is more easily recognizable than our personal email addresses. If you care to contact us, you may use this email address.

Save These Dates

Next Mid-America KIT Meeting

Please plan on attending our next KIT meeting set for 1:00 PM, May 4, 2013 at the Civitan Community Center. Wichita, KS. Dr. Vickie Dukes will address our group.

TMA National Conference

The next TMA Conference will be held October 3 – 6, 2013 in Louisville, KY.

MDA Muscle Walks

- March 2, 2013 at Intrust Bank Arena, Wichita, KS
- March 16, 2012 at Cox Convention Center, Oklahoma City, OK
- March 16, 2013 UMAC, Tulsa, OK



Dr. Dukes will be the guest presenter at our next KIT meeting

The best to all
of you, and
remember,
YOU are NOT
alone!

Mid-America Myositis
Kit

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