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KIT Members
Area #76
Thr Myositis Asociation

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Hi Everyone,

There are many things signaling the winding down of 2008. For starters, there are football, Labor Day, the upcoming Presidential election, the TMA Annual Conference and earlier sunsets. I really like this time of the year as it leads to the great family holidays, Thanksgiving and Christmas. It is also the time to plan for our last KIT family meetings of the year.

Here are the dates of our **upcoming KIT meetings.**

Kansas City---Mark your calendars for **Saturday, November 8th, 1:30 to 3:30 p.m.**

Our meeting will be held at the Landon Center, University of Kansas Medical Center. It is located at **36th and Rainbow Blvd** in Kansas City, Kansas. It is three blocks north of the main campus of KUMC. For more specific directions, please contact me---it seems to be my home away from home---ha! We are very grateful for **Laura Herbelin**, who made the arrangements and provides us with great ongoing support.

Omaha---This meeting is scheduled to be held on **Saturday, September 27th, 1:30 to 3:30 p.m.** Our Nebraska KIT leader, **Laura Deardoff**, will notify you about the location and program.

We had a great meeting in KC on August 16th. There were 25 members and guests in attendance. Here are some highlights taken from the notes of **Jean Linder**. The guest speakers were **Dr. Mazen Dimachkie and Laura Herbelin** from KUMC. They talked about ongoing research and announced that the study of arimoclolmol for **IBM** will be starting soon. People interested in participating are urged to contact Laura, and she will explain how the patient would be involved, and provide the necessary paperwork to sign up for the study. There are some medical conditions that could exclude a person from participating. Dr. Dimachkie mentioned two other studies for IBM, which are gene therapy and lithium. **Kathy Goode, DM, and Cathy Pfeiff. PM**, shared their experiences with their diseases. They provided information pertaining to their diagnosis, treatments and symptoms. Kathy encouraged us to get the book, *Living with Myositis*, which is available on the TMA website. **John Oswalt** talked about the new Golden Lift Chair that he got. It raises you up vertically instead of up and forward at an angle. This puts him on a level so that he can move easily from the chair.

Quilt Raffle---Thanks for your support for this TMA research fund raiser. I had to get two extra orders of tickets. **Sometimes** we tend to think that a dollar or two is not going to make a difference, but what a **BIG** difference a whole bunch of them make.

There is now more research activity on myositis than in the past. I encourage to you to help ourselves and support the TMA research funding campaigns. Let **Bob Goldberg**, TMA Executive Director, know that we appreciate his efforts.

Annual TMA Conference---So far we have four members planning to attend. They are **John Courter, Laura Deardoff, Jean Nolan and Craig Patterson**. Please let me know if you will be there so everyone can be watching for each other.

Home Remedies---This is a handbook that our group put together about four years ago, (my how time flies). It illustrates various home health aids that a person can make or buy to improve the functions of daily living. **Jean Linder** and I will be asking your help to update and revise it. We initially received recognition from **TMA** for it and had several requests from members around the country. We plan to expand it to include information on agencies or people to contact for services that are available for people with disabilities.

Myositis Awareness Day---This is our special day to educate our relatives, friends, acquaintances, in fact the whole world about myositis. We did not plan any special activities this year, but let me know if you need information for your local TV, radio or newspaper reporters. **Remember**, our KIT motto----make everyday Myositis Awareness Day and use the word, “myositis” at least once each day with someone not familiar with it.

E-Mail Users---Thanks for your constant stream of messages. Some are funny and a lot are very inspirational. I try to share as many as possible with our KIT members, hoping not to wear out our welcome. Keep them coming.

Back to our meetings. **As always** remember they are also for spouses, caregivers, or anyone else you wish to bring along. Your attendance provides support for those of us there and gives us the opportunity to support you.

Special note---September marks the **7th Anniversary** of our KIT group. Thanks to everyone for your support and friendship. You have made it successful. Congratulations!

KEEP IN TOUCH, Harley