A FABULOUS OPPORTUNITY FOR OUR KC KIT MEMBERS!

The Myositis Association (TMA) 2010 Annual Patient Conference will be held in St. Louis, Missouri, September 23-25

PLAN TO ATTEND!!

IMPORTANT CONVENTION INFORMATION:

- Research is the focus of the TMA’s conference
- The entire 20 member TMA Medical Advisory Board will be in attendance
- Location: Hilton St. Louis at the Ballpark, Toll-free: 800-Hiltons, e-mail: www.hiltonstlouis.com
- TMA group room rate: $99 per night, this rate applies until 9/26/10.
- Conference registration is $125 for TMA members and $160 for non-members. Conference registration covers meals & materials.
- Refund policy for TMA registration: 100% refund if requested in writing before June 30, 50% refund before August 15.
- The Myositis Association (TMA) office and staff can be reached at 800-821-7356 or www.myositis.org
- TMA address: 1737 King Street, Suite 600, Alexandria, VA 22314
Interestingly, Dr. Dimachkie communicated several important points. The patient should use calcium and vitamin D supplements, monitor blood sugar levels, and have bone density assessments as recommended by your physician. A skin TB test should be administered prior to the initiation of prednisone treatment. Additionally, if patient requires a surgery, an additional “booster” level of prednisone may be required prior to the surgery.

In spite of the numerous side effects, for many patients prednisone remains the first line of treatment for their given type of myositis. In numerous cases prednisone is the only effective treatment available. Therefore, for many, prednisone is truly a life saver.

Newly Diagnosed? Questions? KC KIT Members Do Care!

The Kansas City KIT group has a number of people who are willing to talk with individuals and their families who are either newly diagnosed or who simply want to compare their health condition with someone who is “living their situation”.

Out of the Kansas City area? Our KC KIT group actually encompasses the mid-west with members from several states. Please feel free to contact any of these KIT individuals/liaisons for assistance.

Inclusion Body Myositis (IBM)

Liaison/contacts:
Emery Payne: payneet@sbcglobal.net
Jean Linder: jlinder@eaglecom.net

Dermatomyositis (DM)

Liaison/contacts:
Kathy Goode @ klgooe@msn.com
A C Codner: accodner@gmail.com

Polymyositis (PM)

Liaison/contact:
Dave Hills @ davhills@swbell.net

Necrotizing Myopathy (NM) a form of polymyositis

Liaison/contact:
Jodie Garcia @ jtgarcia8@aol.com
In the Know...

TMA: T(The) M(Myositis) A(Association) News

The 2010 Annual Conference will be in St. Louis, Mo., September 23-25, 2010. Mark your calendar and plan to attend!!

Kansas City KIT –NEXT MEETING!!!!

The next KIT meeting has been scheduled for Saturday, June 5, 2010, 1:30–3:30, Landon Center, University of Kansas, 3599 Rainbow Blvd., Kansas City, KS.

International Myositis Assessment

International Myositis Assessment and Clinical Studies Group is a coalition of healthcare providers and researchers with global approaches to improved treatments and understanding of myositis:

http://dir-apps.niehs.gov/imacs/index.cfm?action=home.main

John Hopkins Myositis Center

John Hopkins Myositis Center is a new patient center that brings the expertise of rheumatologists and neurologists into a single clinic for patients with inflammatory (autoimmune) and toxic (drug induced) muscle conditions.

www.Hopkinsmedicine.org/rheumatology/clinics/myositis_center.html

Online Peer Support

Myositis Association Community Forum:  www.myositis.org
Myositis Support Group:  www.myositissupportgroup.org
Myositis Support Group UK:  www.myositis.org.uk
Yahoo Myositis Support Group Discussion Board:  http://health.groups.yahoo.com/group/OurMyositis
Minutes from March 6, 2010 Meeting, Landon Center, KUMC

Kansas City KIT
Landon Center, KUMC
3599 Rainbow Boulevard
Kansas City, Kansas
March 6, 2010

Meeting to order

The meeting was called to order at 1:30.

Presentation by guest speaker

Dr. Mazen Dimachkie, Neuromuscular specialist, KUMC, discussed the short and long term effects of prednisone use. KIT members were allowed to ask questions following the presentation. Dr Dimachkie also discussed ongoing studies using stem cells in IBM patients and an upcoming study that will look at the genetic make up of patients with PM & DM and who might be more at risk for such types of myositis.

Discussions and group business

The KC KIT group welcomed a visiting family, Tim Lee and wife Kathy. Tim has been diagnosed with DM. All KIT members were given the opportunity to share any information regarding their current health status or any other information pertinent to the group. The group brainstormed ways to get the word out to raise an awareness of all types of myositis. There was also a discussion on how to honor and memorialize our former leader, Harley Russell. The KIT roster has been updated and all members were given a copy. If possible members were encouraged to attend the upcoming TMA Annual Conference to be held September 23-25 in St. Louis. The group discussed the possibility of having a booth at the upcoming MDA’s, Stride and Ride event which is scheduled for March 27. Refreshments were served by the hospitality team and the meeting adjourned.

Next KIT group meeting is scheduled for Saturday, June 5, 2010, Landon Center, 1:30–3:30. *Agenda: funder raiser ideas for TMA, the upcoming TMA Annual Conference to be held in St. Louis Missouri, upcoming events we want to start (Mini Conference).*

March 2010 KIT group meeting attendees

Vernon & Cleta Wells, Darryl Dettmann, Jodie Garcia, Kathy Goode and her father Floyd Marriott, Laura Herbelin, Dr. Dimachkie, Phil & Bobbie Hoffman, Emery Payne, John & Kitty Oswalt, Kathy Pfieff, Jean Linder, Kenneth & Irene Nichols.