

Kansas City KIT

Keep In Touch
The Myositis Association

In Memory of Harley Russell

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
- Agenda: Thursday, "Getting Comfortable", Friday; "Finding a Balance"; Saturday, "Treating Myositis"
- 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

May 2010

KC KIT

Group
Contacts:

Kathy Goode
Group Leader
klgoode@msn.com

John Courter
Assistant Group Leader
jrcourter@sbcglobal.net

Craig Patterson
TMA Board Member
C.patterson@earthlink.net

Jodie Garcia
Newsletter
Jtgarcia8@aol.com

Kitty Oswalt
kios@att.net
and
Bobbie Hoffman
rokchalk01@cox.net
*Care Team and
Communication*

**Next KC KIT Meeting:
June 5, 2010, 1:30 –
3:30, Landon Center**

Dr. Mazen Dimachkie Presents Information on the Use of Prednisone

Dr. Mazen Dimachkie, Neuromuscular Specialist, University of Kansas Medical Center, attended the March 6, 2010 KIT meeting where he discussed the side effects of short-term and long-term use of prednisone and how to counteract the side effects. Common side effects include: weight gain, salt retention, high blood sugar, “moon face”, thinning of the skin, food cravings, emotional swings, bruising, insomnia, eye problems (cataracts, glaucoma), osteoporosis, suppression of immune responses, and in rare cases; bone necrosis.

If long-term use of steroids is necessary 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 @ klgoode@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

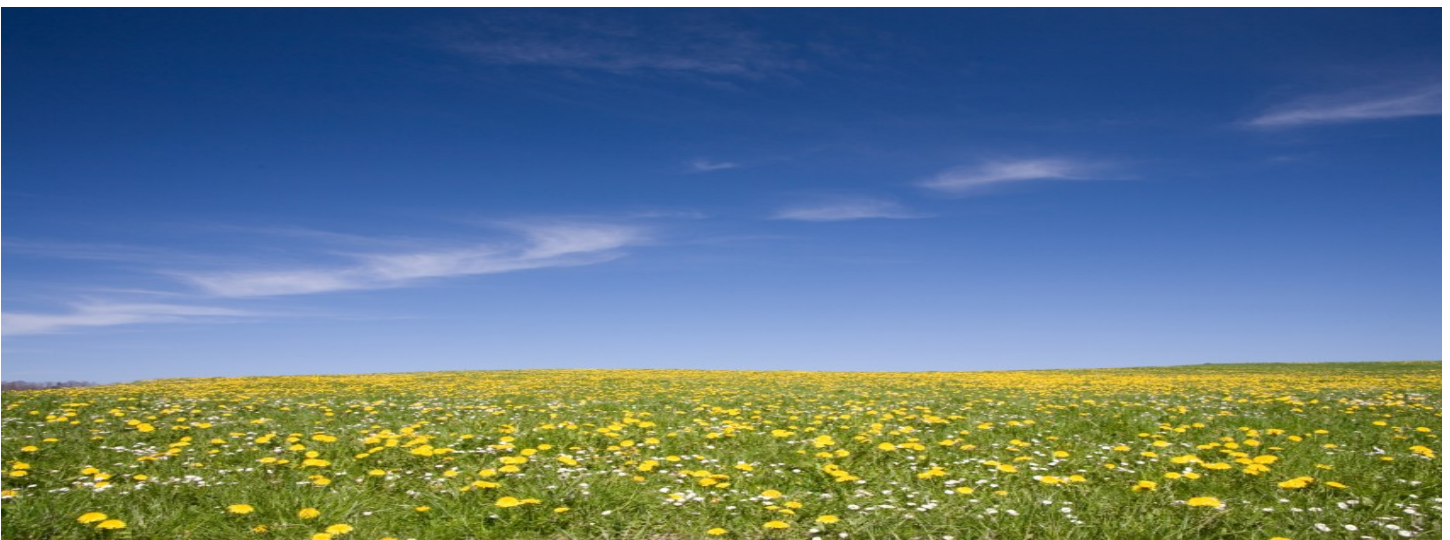
Online Peer Support

Myositis Association Community Forum: www.myositis.org

Myositis Support Group: www.myositissupportgroup.org

Myositis Support Group UK: [www:myositis.org.uk](http://www.myositis.org.uk)

Yahoo Myositis Support Group Discussion Board: <http://health.groups.yahoo.com/group/OurMyosistis>



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 brain stormed 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.