

Kansas City KIT

Keep In Touch
The Myositis Association

In Memory of Harley Russell

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

THE IMPORTANCE OF OUR TMA

A note from: Craig Patterson, KC KIT member & TMA Board Member

Recently Bob Goldberg, TMA executive director, e-mailed a summary of the recent activities of the association. It was an excellent article. If you didn't receive it, call the office at 1-800-821-7356 and get plugged into TMA's e-mail.

This brings me to one of Bob's topics and something we briefly discussed at the last KIT meeting. It is important for you to be a member of TMA. If you don't sign up, TMA doesn't know you have myositis and when TMA is trying to find research dollars, if you can't point to a constituency, it's tough to make an argument that you need research money. The cost is \$35 a year and gives you full access to TMA's very informative web site (www.myositis.org). Please!!!

Bob also mentioned the patient registry being compiled. The purpose of this is to collect background information (where you work, hobbies, etc.) which might, when compared to all persons in the registry, point to a common connection which might shed some light on the origins of our contraction of myositis. There are questions about your work environment, exposure to chemicals, hobbies, such as gardening and lawn chemicals, etc. When you have the opportunity to fill out the questionnaire, please do it. The plan as I understand it is to provide the questionnaire in electronic form for those who have computer access-paper for those who do not. It takes about 20 minutes. The questionnaire is being fine tuned now before being released and the Board members were asked to be guinea pigs on an early draft.

Money and research. From what Bob tells me, there are about 30,000 us lucky folks who have myositis. TMA has a list of about

July, 2010

KC KIT

Group
Contacts:

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*Care Team and
Communication*

**Next KC KIT Meeting:
September 11, 2010,
1:30 -3:30, Landon**

9,000 of those. As a group, we are competing for research funds with other disease groups which are much larger and have developed access to sizable funding over the years. This last year at the January joint meeting of the TMA board and the medical advisory board, we were presented with 4 projects which had survived the screening process of the medical advisory board (there were about 10 good projects submitted). Each project needed \$100,000 in funding spread over a two year period. We chose two of the four. We didn't have the funding for the other two and couldn't risk making a future commitment with funds we did not have.

If 10% of those of us with the disease could spare \$100 a year for research (roughly \$300,000 a year) it would make a tremendous difference. From what I understand, except for the current Department of Defense grant, our research has come as a result of a few wealthy individuals. You can't plan a coherent research program without a continued baseline of support. I think all of us should think about being a part of that baseline.

Annual audited financials are available on line at the TMA website.

Thanks. -Hope to see you at the St. Louis meeting in September. - Craig W. Patterson

Newly Diagnosed? Questions? KC KIT Members Do Care!

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

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".

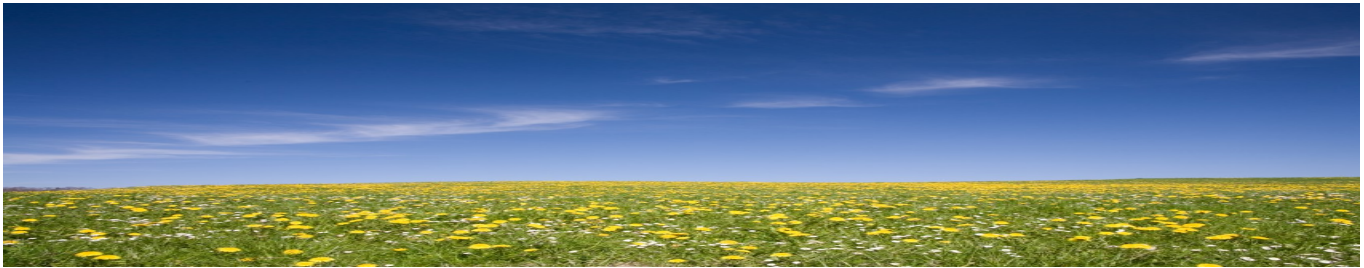
Out of the Kansas City area? Our KC KIT group actually encompasses the mid-west with members from several states. Please feel free to contact any of these KIT individuals/liaisons for assistance.

In the Know...

KC KIT members would like to extend their deepest sympathy to the family of Kenneth Nichols. Charles "Kenneth" Nichols, a resident of Blue Springs, Missouri and Mt. Judea, Arkansas, passed away June 27, 2010 at Centerpoint Medical Center, Independence, Missouri. Kenneth was born March 15, 1926, at Mt. Judea Arkansas, son of Earl and Grace (Sullivan) Nichols. Kenneth was a veteran of WWII, a veteran of the Korean war, and recently received his 50 year pin as a Mason. Kenneth worked for Trans World Airlines for 26 years where he made numerous fishing buddies. Kenneth's family described him as: one who loved deeply, forgave easily, and one who sacrificed much for his family.

Kenneth is survived by Ilene of the home and a son and his wife, a daughter, 2 grandchildren and four step grandchildren.

Kenneth was a long time KC KIT member and fought a very courageous battle with IBM.



IMPORTANT REMINDERS:

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

ONGOING KC KIT FUND RAISING PROJECTS FOR THE TMA:

Our KC KIT chapter is urging all members, family and friends to participate in the TMA on-line campaign and donate \$ toward our goal to raise \$2,000 for the TMA. All donations are tax deductible. Each member that has e-mail will receive info via internet that can be forwarded to other members, family and friends who are interested in donating. The campaign is called: **MO-KAN K.I.T.** campaign. Those members without e-mail will receive this info by newsletter. The address for mail-in donations: **The Myositis Association, 1737 King Street, Suite 600, Alexandria, VA 22314, toll free: 800-821-7356.**

HELP: We need donations from KC area for our TMA silent auction basket. We will be taking the basket to the convention in St. Louis and are in need of items. Contact Jodie Garcia at Jtgarcia8@aol.com if you have items for our basket or bring them to our June 11 meeting. Thanks!

UPCOMING KC KIT MINI-CONFERENCE

Our KC KIT chapter is planning on hosting a mini-conference for patients in June 2011 at the Landon Center, KUMC. If you are interested in helping the planning committee, please contact Kathy Goode at KGOODE@ci.liberty.mo.us or Susan McLoughlin at smcloughlin@mchc.net. Any additional help would be greatly appreciated.

*******SEPTEMBER 21, IS NATIONAL MYOSITIS AWARENESS DAY*******

Minutes from June 5, 2010 Meeting, Landon Center, KUMC

Kansas City KIT, Landon Center, KUMC, 3599 Rainbow Boulevard, Kansas City, Kansas

Meeting to order—June 5, 2010

The meeting was called to order at 1:42.

Discussions and group business

All KIT members introduced themselves and were given the opportunity to share any information regarding their current health status or any other information pertinent to the group. The National Patient Convention to be held in St. Louis, Missouri, September 23-25 was discussed. Group leader, Kathy Goode shared recent correspondence that was received from member, Betsy Wharton, Monticello, IL. Betsy's note included a quick note of thanks for the newsletter, would be in KC area in July, and hope to see other members in St. Louis. Other conference info: Craig Patterson, TMA board member shared that all the TMA Medical Advisory board members are scheduled to be present which is a unique opportunity for KIT members to meet & visit with these individuals. Mr. Patterson also shared information on the financial status of the TMA. He discussed the importance of all members joining the TMA and supporting the only organization that conducts research regarding all types of myositis. Mr. Patterson also stressed the importance of the upcoming myositis registry. Kathy Goode shared all of the TMA's ideas for fund raising opportunities. Currently the annual TMA conference quilt was hand-made by a myositis patient from FL. Raffle tickets are being sold for an opportunity to win the quilt, \$2 for a single ticket, 3 tickets for \$5, 7 tickets for \$10, 20 tickets for \$20. Drawing will be held at the convention. Other TMA sponsored fund raising opportunities: Macy's Shop for a Cause (sell tickets for 1 day shopping pass, cost \$5), Cookie Lee Jewelry Sales-25 % of sales will be donated to the TMA. Contact # 360-929-8330. Additionally, there are 2 race horses, "Myositis Miracle" & "Stop Myositis" who are currently racing in the mid-Atlantic area to raise \$ for the TMA and raise an awareness regarding myositis. "Myositis Miracle" recently won @ the Charles Town Race track and so far has earned \$5,000 for the TMA. It is estimated that the word "myositis" has been heard or seen over 1.3 million times since "Myositis Miracle" has been racing. After some discussion, it was decided that the KC chapter would start (1) an on-line TMA campaign for monetary donations to the TMA and (2) start collecting any items donated by businesses to be raffled off in a silent auction basket at the upcoming convention in St. Louis. Jodie Garcia volunteered to post the on-line campaign for members and families to donate to with all proceeds to the TMA. The group goal was set at \$2,000 by Dec 31, 2010. The assurance that the web site is secure will be verified. KC KIT RAFFLE BASKET. All members brainstormed businesses or individuals that might be able to donate. Possible donors: Chiefs, Royals, Best of KC, Topsy's, chain restaurants (ex: Olive Garden), KC Master Piece, Wizards, Hallmark, LL Bean, Airlines, quilt (Kitty & John Oswalt), Home Depot/Lowes, Wal-Mart, Target, Milwaukee tools, Pottery Barn. Jodie Garcia volunteered to contact as many donors as possible. There was discussion and plans to have a mini-convention at the Landon Center in the summer of 2011. The convention will be chaired by Kathy Goode and Susan McLoughlin. Laura Herbelin, KUMC, agreed to help secure speakers & schedule the Landon Center as our meeting place. More info forthcoming. More volunteers are needed. Several members brainstormed possible ways to honor our late KC KIT founder & member, Harley Russell. A plaque or painting to be displayed at the Landon Center was discussed. There was some discussion of ways to allow more time for socialization time during or following our chapter meetings. Meeting adjourned at 3:50. **NEXT KIT MEETING: SEPTEMBER 11, 2010.**

June 2010 KIT group meeting attendees

Kathy Goode and her father Floyd Marriott, Laura Herbelin, Jodie Garcia, Emery & Therese Payne, John & Kitty Oswalt, Matt & Bev Dengler, Craig Patterson, Jerry & Cindy King, Susan McLoughlin & Steve Gunderson, John & Ruth Courter and daughter.