

Kansas City KIT

Keep In Touch
The Myositis Association

In Memory of Harley Russell

KC KIT MEMBERS SAY “WELCOME” TO OUR CANADIAN VISITORS

On Saturday, October 17, 2009, Gary and Diane IsRalson made their way southward from St. Albert, Alberta Canada to attend our KC KIT meeting. Gary was diagnosed with inclusion body myositis (IBM) in 2004 in Canada. Soon thereafter Gary decided to do his own research and turned to the USA for any ongoing research and studies. The IsRalson's found a study being conducted in Bethesda, Maryland for a drug called Campath. The study involved several trips to National Institutes of Health

(NIH) and eventually Gary was 1 of 20 patients that would be selected for the study. The first 10 patients received the drug (Campath) and Gary was patient 11, which means he did not receive the drug. There did prove to be several side effects to Campath, so the study was halted.

After more searching, another study appeared on the web which was being conducted at the University of Kansas Medical Center. Gary applied and was accepted for an ongoing study

now being conducted through the Neurology Department, KUMC. The IsRalson's were then put in contact with Laura Herbelin, Research Instructor, University of Kansas Medical Center.

While Gary finds IBM a “very frustrating” condition, he maintains that “one must keep positive, and try to be involved in as much research as possible to assist in studies and eventual a cure for this condition”.

January 2010

KC KIT

**Group
Contacts:**

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and
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*Care Team and
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**Next KC KIT Meeting:
March 6, 2010, 1:30 –
3:30, Landon Center**

Dr. April McVey Presents Information on Muscle Biopsies

Dr. April McVey, Neuromuscular Specialist, University of Kansas Medical Center, attended the October 17, 2009 where she discussed and shared a very interesting and informative power point presentation on muscle biopsies of patients with IBM (inclusion body myositis), DM (dermatomyositis), PM (polymyositis) and NM (necrotizing myopathy).

Dr. McVey discussed how important muscle biopsies are to the proper diagnosis of the various muscle diseases. Each type of myositis has some very distinguishing differences when viewed under the microscope. Therefore, muscle biopsies remain one of the more important tools in the total assessment and diagnosis of a particular muscle disease.

Dr. McVey discussed how she performs muscle biopsies which are usually done at the Landon Center under local anesthesiology or some patients may opt for complete sedation with a general surgeon. Following Dr. McVey's presentation, the KC KIT members were allowed time to ask questions.

Much thanks to Dr. McVey for taking her time to attend our meeting and help educate our group on muscle biopsies.

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:

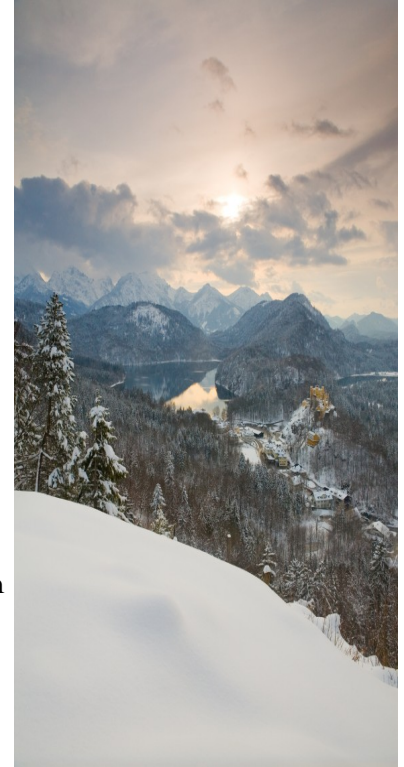
Jodie Garcia @ jtgarcia8@aol.com

UPDATE ON OUR MEMBERS

IN LOVING MEMORY OF ANTHONY (TONY) STANISLAUS MCGRATH

Family, friends, and colleagues would like to extend their deepest sympathy to the family of long time KC KIT member, Tony McGrath. Tony passed away at the age of 79 years after a lengthy battle with inclusion body myositis. Tony is survived by his wife of 55 years, Gladys; daughter Colleen and her husband Hal Galbraith, daughter Mary and her husband Richard Wiggins, son Kevin and his wife Vicki McGrath, daughter Patricia Crawford, daughter Maureen and her husband Carl Schmittgens, brother Daniel and sister-in-law Charlotte McCrath and 12 grandchildren.

Tony entered the United States Navy in 1952 where he served aboard a steam driven vessel, the Daniel A. Joy. On January 23, 1954, Tony and Gladys June Egloff were married in Lemont, Illinois. After relocating to Kansas City, Tony attended Pharmacy School at the University of Kansas City Pharmacy school, where he graduated with honors. In 1963, Tony and his brother Francis McGrath opened the first McGrath Prescription Shop on Blue Ridge Boulevard. The McGrath brothers went on to open four more prescription shops in the Kansas City area. The McGrath Prescription Shops were also known for being one of their first pharmacies to offer the convenience of drive-up prescription service. Tony was also a longtime member of St. Catherine's Catholic Church.



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, watch for more information. This would be a great opportunity to attend.

Kansas City KIT News

The next KIT meeting has been scheduled for March 6, 2010, 1:30–3:30, Landon Center, University of Kansas, 3599 Rainbow Blvd., Kansas City, KS.

Dr. Mazen Dimachkie, Neuromuscular Specialist, University of Kansas Medical Center, will be our featured speaker at our March 6, 2010 meeting. Dr. Dimachkie will be talk about prednisone, the side effects, and how to counteract the side effects of prednisone.

Local News

The MDA is another great resource for myositis patients and families. Contact Angie Hills e-mail: ahills@mdausa.org or phone: 913-451-3230. The MDA has now scheduled their 4th Annual Stride & Ride event for March 27, 2010. The money raised will stay in the local area to help families living with Neuromuscular Disease.

Minutes from October 17, 2009 Meeting, Landon Center, KUMC

Kansas City KIT
Landon Center, KUMC
3599 Rainbow Boulevard
Kansas City, Kansas
October 17, 2009

Meeting to order

The meeting was called to order at 1:30.

Presentation by guest speaker

Dr. April McVey, Neuromuscular specialist, KUMC, shared a power point presentation of muscle biopsies from inclusion body, polymyositis, dermatomyositis, and necrotizing myopathy slides. KIT members were allowed to ask questions following the presentation.

Discussions and group business

The KC KIT group welcomed 2 new families. New attendees included: Susan McLoughlin and Steve Gunderson of Overland Park, Kansas. Susan was just recently diagnosed with dermatomyositis. Also in attendance was Mr. & Mrs. Gary IsRalson of St. Albert, Alberta Canada. Gary has inclusion body myositis. All members were given an opportunity to share any information regarding their current health status or any other information pertinent to the group. Numerous group members shared their condolences to the family of Tony McGrath who passed away October 13, 2009. Tony courageously battled inclusion body myositis for a number of years. KC KIT member Phil Hoffman shared his helpful idea of putting a rubber thumb guard on his thumb/fingers to help pick up papers. The current KC KIT group roster is in need of updating. The update should be available at the next KC KIT meeting. Refreshments were served by the hospitality team and the meeting adjourned.

Next KIT group meeting is scheduled for Saturday, March 6, 2010, Landon Center, 1:30–3:30. The featured speaker will be Dr. Dimachkie who will speaking on prednisone and the side effects of the drug.

October 2009 KIT group meeting attendees

John & Ruth Courter, Darryl Dettmann, Jodie Garcia, Kathy Goode, Laura Herbelin, Phil & Bobbie Hoffman, Gary & Dianne IsRalson, Susan McLoughlin & Steve Gunderson, Dr. McVey and daughter, Jean Nolan, John & Kitty Oswalt, Emery & Therese Payne, Kathy Pfeiff.