

MID-AMERICA MYOSITIS KIT

*Welcome to another edition of
your KIT newsletter*

Special Guest Speaker at Next Kit Meeting

Dr. Robert Wortmann, a renowned physician with mega-experience in Myositis will be traveling from his home in New Hampshire to Wichita to address and visit with myositis patients and caregivers at our next KIT (Keep In Touch) meeting. The meeting is now scheduled for **November 2nd**, 2013 at **12 NOON until approximately 3 PM.** The early start provides us some additional time to query Dr. Wortmann and also allows him the ability to catch a flight home that same afternoon.

Dr. Wortmann will be first on the agenda at the

meeting, so please plan on being there before 12 noon!

Dr. Wortmann has 38 years of experience in his practice of Rheumatology and has gained considerable expertise in studying muscle diseases like myositis.

Let's give him a warm welcome on November 2nd, **12:00** noon, at the Civitan Community Center, 901 Porter St., Wichita, KS.



Dr. Wortmann

NOTE: To allow planning for this special event, please RSVP your intentions to attend. Please send an email

with the number of attendees in your group to:
mid_america_myositis@aol.com

or call 316-207-6230

Novartis Drug for IBM Placed on Fast Track

Novartis has received breakthrough therapy designation to BYM338 from the US Food and Drug Administration (FDA) for sporadic inclusion body myositis (sIBM).

Breakthrough therapy designation was created by the FDA to expedite the development and review of new drugs for serious or life-threatening conditions. This designation is based on the results of a Phase II proof-of-concept study that showed BYM338 substantially benefited patients with sIBM compared to placebo. The results of this study will be presented at the American Neurological Association meeting on October 14 and

is expected to be published in a major medical journal later this year.

BYM338 (bimagrumab) is a novel, fully human monoclonal antibody developed to treat pathological muscle loss and weakness. BYM338 was developed by the Novartis Institutes for Biomedical Research (NIBR), in collaboration with Morphosys, whose HuCAL library was used to identify the antibody. BYM338 binds with high affinity to type II activin receptors, preventing natural ligands from binding, including myostatin and activin. BYM338 stimulates muscle growth by blocking signaling from these inhibitory molecules.

According to the FDA, breakthrough therapy designation is intended to expedite the development and review of drugs that treat serious or life-threatening conditions. The designation requires preliminary clinical evidence that demonstrates

substantial improvement over currently available therapy. The designation includes all of the fast track program features, as well as more intensive FDA interaction and guidance. The breakthrough therapy designation is a distinct status from both accelerated approval and priority review, which can also be granted to the same drug if relevant criteria are met.

Let's Keep Our Fingers Crossed!

MDA funds research that could help DM & PM

The Muscular Dystrophy Association (MDA) awards \$8.5 Million to 31 neuromuscular disease research projects including Dysferlinopathies. Dysferlinopathies are muscle diseases caused by mutations in the dysferlin gene, an important muscle repair protein.

If these research efforts prove useful in dysferlinopathies, they may have potential for other muscle diseases as well, including Duchenne muscular dystrophy, **dermatomyositis**, **polymyositis**, myasthenia gravis and Lambert-Eaton myasthenic syndrome.

KS/OK Raffle Basket

We are still looking for items donated by KS/OK businesses that will be included in the Gift Basket to be raffled off at the national myositis convention in mid-October. Get your items to your KIT leaders as soon as possible.

If your address changes.....

Keeping our records up-to-date requires your involvement. Our KIT and the national TMA need your updates any time any critical information about your location or address occurs. Please forward any address

changes (home, street or City/St/Zip) or any email address changes. Making these changes will insure the delivery of any myositis information. Please send any changes to one of your Mid-America Myositis KIT leaders and we will forward them on to the national office after updating our records.



Save These Dates

Next Mid-America KIT Meeting

Please plan on attending our next KIT meeting set for **12:00 PM**, Saturday November 2nd, 2013 at the Civitan Community Center. 901 Porter St., Wichita, KS.

Dr. Robert Wortmann from Mary Hitchcock Memorial

Hospital, Lebanon, NH will be the guest presenter.

TMA National Conference

The next TMA National Conference will be held October 17-20, 2013 in Louisville, KY. If you have decided to attend, please contact TMA to make your registration.

Local MDA Events

- 10/17 Young Adult Support Group
- 10/19 Muscle Walk Kickoff
- 11/7 ALS Support Group

Mid-America Myositis Kit
(Keep-In-Touch)
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