Mid- America Myositis KIT

What is the Mid-America Myositis KIT?

In Fall of 2012, Jerry King & Carolyn Ester, both diagnosed with Inclusion Body Myositis, decided to initiate a KIT (Keep in Touch) group sponsored by The Myositis Association for the South Kansas area. We expanded our area of coverage when we learned that Oklahoma did not have a KIT group in their state at the present time. 15 months later, our KIT group is in contact with over 60 people in South Kansas or Northern Oklahoma that have myositis of one type or another. Our ages and conditions run the gamut from young adults to 80 year olds and while some of us are wheelchair bound, others are relatively healthy and able to lead normal lives.

We organized in early 2012 to be a support network for people who in many cases, had never even spoken to another Myositis patient. We hold quarterly meetings with time for sharing, and try to schedule speaker for every meeting.

Some members have been to every meeting and some have not been to one. We follow up with e-mail newsletters, often with pictures of those who did attend. Our whole purpose is to live our motto, which is:

"We Care,
So Come And Share"

Our Meeting Place Host

Civitan has prestigious recognition in the world of volunteer service organizations. Working through their clubs Civitan hands seek out community needs and then work to fulfill them projects are selected at the local club level-each club determines its own projects programs of work. This way each club is uniquely responsive to its community. Civitan places major emphasis on projects which assist people with developmental disabilities. Civitan members provide assistance at the local Special Olympics, Salvation Army, scholarships with Friends University, and work on projects that support the removal of architectural barriers for handicapped people in the Wichita area. They also provide financial assistance to:

- the ARC of Sedgwick County Circle of Friends Program
- Civitan Community House
- Civitan International Research Ctr.
- Fresh Air Baby Restoration
- Junior Civitan
- Lords Diner
- Operation Holidays
- The Salvation Army
- The Independent Special Olympic Teams
- …and more

We thank the Civitan organization for allowing our KIT group to meeting in their Community House.

The Myositis Association (TMA)

In 2012 this organization is over 20 years old and has an impressive history of supporting those with Myositis diseases. Based in Alexandria, VA, it provides assistance both to individuals and groups. It also has funded over $3 million for research into causes and treatments of Myositis.

Their website, www.myositis.org has a wealth of information for patients and their families. Membership is free. They hold an annual conference, attended by up to 400. Their on-line bulletin board, webinars with medical experts and equipment exchange are all geared to help those of us with Myositis to feel that we are not alone.

Through TMA, KITs have been formed all around the US. By keeping in touch with each other, we strengthen our individual groups, learning from the experiences of our fellow KITs.

Why Join Us?

Having a rare and incurable (but controllable) disease is for many of us a frightening thing. Having contact, whether face-to-face, by phone or e-mail, is a definite comfort. We have no dues or membership requirements; just an interest in "Keeping In Touch."

By joining TMA and our KIT, you become part of a family that is learning how to cope with Myositis.

We don't ask a lot of you; we want to find ways to give you hope, support and comfort.

At our meetings, many feel the time we spend sharing what's happening in our lives is the best part of the event. We share experiences with therapies and other issues. We also advocate for The Myositis Association which brought us together.

All who have, or know someone with one of these diseases, are welcome to come to our meetings!

Contacts:
To find out more and to join TMA, call or go to their website:

The Myositis Association (TMA)
1737 King St., Suite 600
Alexandria, VA 22314-2727
800-821-7356
www.myositis.org

To find out more or to join our KIT, call or e-mail one of the members listed below:

Jerry King
316-207-6230
mid_am_myositis@AOL.com

Carolyn Ester
316-259 2662

"We Care,
So Come and Share"

If you, or someone you know has been diagnosed with a Myositis Disease, please read this newsletter…. YOU ARE NOT ALONE!

Our Previous Meeting

We were blessed with the visit from Dr. Robert Wortmann from New Hampshire. Dr. Wortmann recently retired from his profession, but continues towards the advocacy and support of myositis patients.

Dr. Wortmann converses with Brent Clark before the meeting

Dr. Wortmann spoke of his experiences during his professional career with the various myositis's. He shared a lot of knowledge with those that were present, and spent an hour and 45 minutes speaking to our group. Prior to the meeting he was there one hour early to speak one-on-one with all people who had arrived early.

Our Next Meeting

Our next Mid-America Myositis KIT meeting is scheduled for Saturday, April 26 from 1 PM to 3 PM. Our meeting will be held at the Civitan Community Center at 901 Porter St., Wichita, KS.

We will have three guest speakers at this next meeting. A representative from MDA will give a presentation about what benefits we can reap from their organization. PM, DM, and IBM are all diseases that fall under the umbrella of the Muscular Dystrophy Association.

We're also fortunate enough to have two special presenters at our next meeting. They will present to us their story about dermatomyositis, the trials and tribulations, and also the treatments that it led to the remission of dermatomyositis. The spouse will give a short presentation covering the identical time span from a caregiver's standpoint.
Our regular meeting discussions will follow.

We have grown membership and attendance at each and every one of our meetings and we hope to experience the same at this upcoming event.

Please mark your calendar and plan on attending this next meeting on April 26.

Please Understand

Please Understand…

These are the things that I would like you to understand about my having a Myositis disease.

I often spend some of my day in pain and exhaustion, and if you visit I probably don't seem like "myself", but I'm still me inside this body. I still care about life, work, my family and friends, and the outside world, and most of the time I'd like to hear you talk about them.

Please understand the difference between "happy" and "healthy." When you are sick, you probably feel miserable, but I've been sick for a long time. I can't be miserable all the time, in fact I work hard at not being miserable. So if you're talking to me and I sound happy, it means I'm happy. That's all. It doesn't mean that I'm not in pain, or tired, or that I'm getting better, or any of those things. Please, don't say "oh, you're sounding better." I am not sounding better; I am sounding happy. If you want to comment on that, you're welcome to.

Please understand that being able to stand up for 10 minutes doesn't necessarily mean that I can stand up for 20 minutes, or an hour. And, just because I managed to stand for 30 minutes yesterday doesn't mean that I can do the same today.

Please repeat the above paragraph substituting, "sitting," "walking," "being sociable" and so on...it applies to everything. That's what Myositis does to you. Please understand that these illnesses are variable. It's quite possible that one day I am able to walk to the park and back, while the next day I have trouble getting to the kitchen. Please don't say to me when I'm ill, "but you did it before!". I may be working in the yard one week, but letting my yard go the next. It is confusing, especially to me, so please don't question what I have done in the past.

In a similar vein, I may need to cancel an invitation at the last minute. If this happens please don't take it personally. Please understand that "getting out and doing things" does not make me feel better. Telling me that I need a treadmill, or that I need to lose (or gain) weight, try these classes...may frustrate me to tears. If I was capable of doing these things, don't you know that I would? I am working with my doctors and am already doing the diet and exercise that I am supposed to do. I know my body, and know what it is capable of. Don't you think it practically kills me, to not be able to do what I used to do?

Please stop telling me to "have a positive attitude, or do this you'll feel better, get out more, think better thoughts, slow down, rest more, sleep less, etc". I constantly try to find what suits me; it consumes me more than you could ever know. Don't compare me to someone who had a disease, but was able to do this, or Cousin Fred, who had something similar and he used this. I spend hours reading and trying to find information; I am an individual, not a statistic.

You have no idea of how hard some tasks are for me; just going to a store, doing chores around the house, etc. I look back at what I could accomplish in the past, and now it takes twice as long to do half as much. Don't you think that hurts? I have had my dreams and life goals tuned upside down. I have all of the things in life to battle with like other people: stressful jobs, money, children or family problems, cars that break down, holiday stress, etc., plus I have a devastating, incurable disease.
(Excerpt from TMA material)

Improving our KIT

Opportunities to help our KIT Support Group:

We're all busy and our energy and strength varies from day to day. But sometimes when we give to others, like by helping to put together one of these meetings, and other activities, it takes our minds off ourselves and lets us focus on others.

If you'd like to help, even in a very small way, here's your chance to volunteer. There is no obligation in the sense that if you find yourself in a flare or maybe even an “I just don’t think I can do it today” mood, it’s no problem; we’ll ask again, another time.

Please consider signing up to help with one of these “opportunities”. If you want to volunteer or just want more information before you commit, please contact Jerry or Carolyn

Meeting Activities (some of these are usually donated; some are paid for by the KIT)

Bring beverages

Bring desserts

Help with room set up and/or clean up

Find sponsors to help with meeting expenses

Arrange for speakers or presentations

Publicity/Media

Contact media outlets about upcoming meetings and activities

Act as photographer at a meeting or event

Member Support

Make occasional phone calls or sending e-mails to homebound members or a person you met at the last KIT meeting.

Purchase cards for members to sign and send

Send flowers to very ill members

Act as an ‘ambassador’ to new TMA members

Dysphagia

Difficulty Swallowing (Dysphagia) - Overview

What is difficulty swallowing (dysphagia)?

Difficulty swallowing is also called dysphagia. It is usually a sign of a problem with your throat or esophagus, the muscular tube that moves food and liquids from the back of your mouth to your stomach. Although dysphagia can happen to anyone, it is most common in older adults, babies, and people who have problems of the brain or nervous system.

There are many different problems that can prevent the throat or esophagus from working properly. Some of these are minor, and others are more serious. If you have a hard time swallowing once or twice, you probably do not have a medical problem. But if you have trouble swallowing on a regular basis, you may have a more serious problem that needs treatment. **What causes dysphagia?**

Normally, the muscles in your throat and esophagus squeeze, or contract, to move food and liquids from your mouth to your stomach without problems. Sometimes, though, food and liquids have trouble getting to your stomach. There are two types of problems that can make it hard for food and liquids to travel down your esophagus:

- The muscles and nerves that help move food through the throat and esophagus are not working right. This can happen if you have:
    - Certain problems with your nervous system, such as post-polio syndrome, multiple

    sclerosis, muscular dystrophy, or Parkinson's disease.
    - An immune system problem that causes swelling (or inflammation) and weakness, such as **polymyositis or dermatomyositis, or Inclusion Body Myositis.**

If you notice that it is more difficult to swallow or pieces of food seem to get stuck in your throat, it's time for you to visit a doctor who specializes in the throat and throat muscles.
Their treatments may range from speech therapy to a throat stretching procedure to a feeding tube in most severe cases.

Next National Conference

The next annual patient conference will be held in Reno Nevada September 4 through the 7th, 2014 in Reno Nevada, at the Peppermill Resort. The TMA group room rate price is $85 per night. Reservations can be made by phoning 1-800-282-2444.
The Peppermill resort has 1,623 luxurious guest rooms, 10 restaurants and 15 bars and lounges, free nightly entertainment in some of the lounges, and to resort pools as well as a three-story spa to soothe your pains away.

Conference registration completed by May 31 will cost $165, by July 10- $195, after August 4- $245.

Contact your group leaders for more information.

To our Caregivers

THANK YOU FOR BEING THERE
From those with diseases rare
We thank all those who really care,
Mothers, sisters, daughters, sons
Fathers, friends and little ones
Thank you for being there
The help out of bed
When we're feeling half dead
When the quick little shower
Can take half an hour
When we battle to eat
And trip over our feet
The lift into chair
The combing of hair
Thank you for being there
When we're rather grumpy
And life is quite bumpy
We don't mean to bug you
And we'd much rather hug you
Thank you for being there
We rely on our charms
Cause we can't use our arms
Please hug us a lot
We need all that you've got
We rely on your touch
And we love you so much
Thank you for being there
When we can't wash the dishes
Despite our best wishes
When we can't mow the grass
And are a pain in the…..
Thank you for being there
We love you and thank you with all of our hearts
If only we could, we would bake you some tarts
Thank you for being there.

Submitted by: Roly Clulow

Mid- America Myositis KIT

Reminder

Our next Mid-America Myositis Meeting is scheduled for 1-3 pm
on April 26, 2014 at the Civitan Community Center,
901 Porter St., Wichita KS

Directions to the Civitan Center in Wichita, KS

From Kellogg Avenue, take the Seneca Street exit.
Turn north on Seneca and travel approximately 1.1 mile to McLean Blvd.
Proceed north on Seneca another 0.1 mile, turning left on W. Museum Bvld.
Turn a quick slight right onto Stackman Drive.
Turn left onto West Pine St. Travel west two blocks.
Turn north onto Porter St. Proceed north on Porter for two blocks.
The Civitan Center is located on the Corner of Porter and W. Franklin.