MYOSITIS SUPPORT GROUP

Washington, D.C.; Maryland; Northern Virginia and Delaware

Connected by Myositis and the Chesapeake Bay!

Newsletter September 2015

Our August 1st meeting gave us an opportunity to spend quality time with Dr. Andrew Mammen, MD., PhD who is an Adjunct Professor at Johns Hopkins department of Neurology and Medicine and works in research at National Instituted of Health. Dr. Mammen sees patients with diseases affecting muscles and his research focuses on statin-triggered muscle disease, muscle regeneration in myositis, as well as the link between myositis and cancer. Dr. Mammen still sees patients at Johns Hopkins two days a month. We were reminded of the clinical features of DM, PM, IBM. At the same time examining the slides of normal and diseased muscle biopsy to understand how the different types of myositis are diagnosed. There are 2 types of remission

1. Pharmacological – meaning the patient can feel normal with treatment.
2. True Remission – Treatment is gradually taken away as patient is feeling normal and continues to feel normal without the treatment.

CK levels are not an issue as much as whether you are able to do the things you want to do. There is some discussion on whether IBM is an autoimmune disease or is there something wrong with the muscle itself. A great deal of time was spent on the effects of statins on myositis, the importance of exercise to make the muscles as strong as they can be and measures being taken to educate our present doctors and our students in Medical School. TMA supports this endeavor.

Dr. Mammen and his team are trying to get Hopkins and NIH working together to share data and research findings. NIH is a research Hospital not a long term care facility where as Johns Hopkins best cares for the patients over a long period of time. For the trials presently going on go to www.myositis.org.   Tremendous amounts of information was shared in the presentation and the Question and Answer session dealt with specific concerns of those present.

Thank you Dr. Mammen for doing such an outstanding job. Everyone left feeling much more knowledgeable and hopeful.

TMA Videos

Sometimes a video is worth many hundreds of words, and you'll find lots of information in TMA's videos, whether instructions, stories, or sessions from TMA Patient Conferences. TMA videos help you understand myositis and include practical information.

TMA has sponsored and produced videos to give you visual help in understanding life with myositis as well as introducing practical information.

- New Patient Stories
- Annual Patient Conference Sessions – New ones to be posted for the 2015 Conference
- Exercise
- Dysphagia
- Preventing Falls
- Caregiver Conversations

Did you know that the TMA web site has a complete guide to vitamins

and supplements?

Our Run/Walk is coming up please call to volunteer to help make calls, send out flyers, man the tables, donate to the silent auction, form a team to walk or run, or just see where the need is. The flyer for

If you haven't had a chance to attend one of our meetings please do so in November. Our meetings begin with a potluck (always delicious), presentation, discussion, and then we break into disease types. We need your insights, positive vibes, and your wisdom.

<u>**2015 MEETING DATES – at 1:00 PM – 4PM The first Saturday Hosted by the Support Group**</u>

- February 7th
- May 2nd
- August 1st
- **November 7th**

Please know we care and you will be welcomed with open arms.   There is always time to share and learn new things.   Research has shown that people who receive support from a social network cope better, feel more in control and have a better outcome than those who are isolated. WE NEED YOU!

<u>With Sympathy and in Friendship we say good–bye to two friends</u>

Raymond Dunton sadly passed away several months ago.   Raymond attended several of our first support group meetings and will definitely be missed.   Raymond was featured in TMA's newsletter relating his experience with IBM and sharing his book "Talking to You".

Paul Scheerer has also passed away. Paul and his wife Sue frequented our Support Group meetings. He was such a kind man and will certainly be missed. Paul suffered from Polymyositis.

Please wear Blue on 21st September in support of Awareness of Myositis.

Myositis Awareness
Day
September 21st
CURE MYOSITIS
Educate   Donate
www.myositis.org

A FEW BAD DAYS
DOESN'T MAKE IT
A BAD LIFE. SO
GET UP AND
KEEP MOVING
FORWARD
POSITIVELIFETIPS.COM

MYOSITIS 5K

Run, Walk N' Roll

Saturday, October 24th 2015

Centennial Park, 10000 Route 108, Ellicott City, MD.

Register or Donate on-line: (http://getmeregistered.com/Myositis5K) or scan the QR code below! NOTE: Early registration insures receipt of a T-Shirt. You may also use the registration form on the reverse of this flyer to mail your registration or make a donation.

JOHNS HOPKINS MEDICINE

Proceeds benefit the Johns Hopkins Myositis Center and The Myositis Association in search for a cure for this rare disease.

DAY PRIOR 5-7PM Early Packet Pick Up - Charm City Run, 12186 Clarksville Pke, Clarksville, MD
RACE DAY 8AM Registration and Packet Pick-up
8:45 AM Welcome and Warm Up Activity
9:00 AM 5K Run
9:30 – 1200 Walk N' Roll

Registration Fees:*
Adults $25.00 ($30 after Oct 10th)
Under 13 $15.00
(Register by Oct 11th to insure T-shirt size)
* A processing fee of $2.48 will be added for on-line registrations.

Also available: Free massage therapy demos, silent auction, specialty information tables, Instructor-led warm up exercises, 50/50 drawing.

Please Help: Myositis is a rare, life-altering autoimmune disease that can cause muscle damage, pain, fatigue, weakness, and death. For many who suffer from the illness, it is a challenge to stand up, get out of bed, walk, or to perform other simple day to day activities. Some forms of the disease may also damage the skin and attack major organs of the body. For More Information please contact: Jenny Leonard at jennysilverb@yahoo.com or call 770-891-3966; or Bitsy Anderson at terrybitsy@verizon.net or 410-987-8407.