



# THE MYOSITIS ASSOCIATION

## KEEP IN TOUCH

### Washington, D.C., Northern Virginia, Maryland, Delaware KIT Newsletter April 2013

#### Special Events

1. Future Meetings 1pm-4pm  
April 6<sup>th</sup>, July 13<sup>th</sup>, December 7<sup>th</sup>  
Meetings are held at Our Land of the Fields Catholic Church  
1070 Cecil Ave. S.; Millersville, MD 21108
2. 2013 Annual Patient Conference  
Louisville, Kentucky  
October 17 – 20<sup>th</sup>
3. October 26<sup>th</sup>, 2013; 9am-1pm  
Myositis Halloween Run, Walk N' Roll  
Centennial Park, Ellicott City, MD

Please join us the Saturday of **April 6<sup>th</sup>**. Dr. Christopher Stine will be sharing her knowledge of the Myositis Disease. There will be a potluck so bring something to share. **We also will be discussing the details of the Walk. Time to start recruiting teams and volunteers.**

#### **RECAP FROM THE MARCH 2<sup>nd</sup> MEETING**

- Be a partner with your Doctor and be active in the decision making. Don't hesitate to speak up if you don't agree or understand something. Ask lots of questions.
- Know your disease by checking out Internet Research, Mayo Clinic, NIH and Johns Hopkins.
- Listen to your body

- Get copies of all records, doctor appointments, blood work, all tests and keep a medical flash drive.
- Talk with others with Myositis about treatment and what has worked for them.
- Take detail notes when speaking to insurance companies. Get the name and ID of the person you're talking with.
- Be persistent with your providers and your insurance carrier.
- Practice speaking openly about your needs and strengths with family and friends.

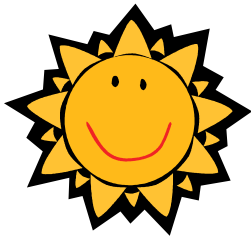
## NEWS:

1. Acthar Now Available as a Treatment for Dermatomyositis and Polymyositis. Dermatomyositis and Polymyositis patients now have another treatment option to consider. Check out the update information on the website [www.myositis.org](http://www.myositis.org).
2. Check out the video on "Fall Prevention" and Dysphagia on the TMA website.
3. TMA is taking an initiative towards physician education. The Medical Advisory Board is to visit medical schools to educate young doctors about Myositis.
4. **Mindfulness Meditation for the Management of Chronic Disease. The purpose of meditation:** Is to pay attention. The practice of paying attention, cultivates the ability to observe and focus, which leads to the ability to see more clearly without mind chatter and static to fragment attention and thinking. With Practice the ability to pay attention will create the ability to know one's self. To know oneself is difficult for most, as we are often playing rolls in our life, and act out of preconditioned thoughts and responses that reinforce our ability to always end up in the same place without much evolved progress. Many of us are unaware of how we feel, our feelings mostly blocked or dramatized by the brain. To get to know our feeling body is a powerful skill that enhances personal intimacy. Meditation is like turning down the volume, on the busyness of the day, and the busyness of the mind. We often get tied up in regrets or wariness caused by past events, or worries about the future, all of which limit the amount of attention we are free to give the present moment. Meaning we are typically only half here, extending half an effort into our day to day moment to moment life situation. Too often we make lightning fast decisions based our past experience. Which is ok, however, if we want different results then we have achieved in the past, we must consciously slow things down enough to be aware of what we are setting ourselves up for, the same old thing that is not working, again without awareness. For a plan go to the website and the presentations from the 2012 Patient Conference.

## 5. Tips for Family Caregivers

- Care giving is a job and respite is your earned right. Reward yourself with respite breaks often.
- Watch out for signs of depression and don't delay in getting professional help when you need it.

- When people offer to help, accept the offer and suggest specific things they can do.
- Educate yourself about your loved one's condition and how to communicate effectively with the doctors.
- There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
- Seek support from other caregivers. There is great strength in knowing you are not alone.
- Stand up for your rights as a caregiver and a citizen.
- Trust your instincts. Most of the time they'll lead you in the right direction.
- Grieve for your losses, and allow yourself to dream new dreams.
- Seek support from other caregivers. There is great strength in knowing you are not alone.
- **Messages for Family Caregivers to Live By**  
 Believe in yourself.  
 Protect your health.  
 Reach out for help.  
 Speak up for your rights.  
 Stand up for your rights as a caregiver and a citizen.



***When the best things are not possible,  
 the best may be made of those that are.***  
 Richard Hooker

**If any questions or concerns you may contact:  
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**Ideas you'd like to see in the newsletter contact:  
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