

THE MYOSITIS ASSOCIATION

KEEP IN TOUCH

Washington, D.C., Maryland, Northern Virginia and Delaware Kit
Newsletter

January 2013

SPECIAL EVENTS

1. Future meetings from 1pm–4:00 pm on **January 26**, **April 6th**, **July 13th**, **December 7th**. Meeting at Our Lady of the Fields 1070 Cecil Ave. S, Millersville, MD 21108
2. 2013 Annual Patient **Conference** will be in Louisville, Kentucky, **October 17th-20th**, 2013.
3. October 26th, 2013. Annual Walk for a Cure. 9:00 am–1:00 pm. Centennial Park, Ellicott City, MD.
1. Bring your ideas to the January meeting.
2. Decide where your talents are and help us raise money for research.
3. We need you and we want this to be your group !
4. We want a cure for everyone and working together we can make a difference!!!

Why should I attend a support group?

Those with Myositis face the difficulty dealing with a chronic illness, plus the extra challenge of having a rare disease most people have never heard of. Because the disease is so rare, it's hard to find others who understand what you are going through and the challenges posed by Myositis. TMA helps resolve this problem through its **Keep In Touch (KIT)** member support network. Our KIT group will offer members the chance to join with others in our area and share mutual support, friend-

ship and ideas.

Research has found that people who receive support from a social network cope better, feel more in control and have better outcomes than those who are isolated. The volunteer leaders who manage our support group devote their personal time and energy to organize and encourage communication among local TMA members. KIT members interact with each other through face-to-face support group meetings, newsletters, telephone and e-mails. We

have regularly scheduled meetings with speakers, meals and local activities.

If you are looking to talk with others about your disease to gain a better understanding and prepare for the challenges ahead, you are encouraged to join the KIT support group.



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Created to provide support for patients and families. Provide communication between medical advisory board, general medical

Members Input

What are some areas that you'd like to know more about? Are there speakers that we could get to answer some of your questions? Please send suggestions to terrybitsy@verizon.net / 410-987-8407 or jennysilverb@yahoo.com / 1-770-891-3966 & we'll see what we can do for future meetings. Also email or call if you want to volunteer for the walk.

Happiness is like a kiss. You have to share it to enjoy it.



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Falls can happen at any time--even as soon as today. If you are considering a medical alert system to protect yourself or a family member, please don't delay. Here are a few resources you may want to consider.

1. MED-ALERT—1-800-633-2537 comes with a 20 hour battery back up if electricity goes out.
2. ALERT-MED—1-888-420-4751 online offer only \$19.95/ per month, free equipment. No start-up costs, month to month agreement.
3. MEDFIRSTALERT 1-800-595-0718 \$24.95/ mon. No annual contract, cancel anytime, 24/7 customer service, 5 min. set up.
4. LIFELINK—no monthly fees. It's a one time fee up front for equipment. The client wears a pendant or can press a button on the machine and there is a choice of calling a family member, neighbor, or 911. Could be sponsored by your local hospital.
5. PHILLIPS LIFELINE— 1-800-566-6218 No equipment to buy no long term contracts, no hidden fees,
6. WALMARTS LOGIC MARK FREEDOM ALERT EMERGENCY ALERT SYSTEM— Online it sells for \$279.95, no monthly fees, activation fees or contracts. It is water resistant and comes with three methods of carrying pendant.

Gene Therapy Trial

IBM: Follistatin Gene Therapy Trial Update - treatment of the 9 IBM patients is proceeding but not as fast as had been hoped. The first 3 IBM patients have been treated and 6 remain to be treated. Results of the trial will not be known until all 9 have been treated and evaluated since there are three groups of 3 patients with each group getting a different treatment - the first group was injected in only one leg; the second group will be injected in both legs; and the last group will receive a higher dosage in both legs than the second group. Results of the treatments between the 3 groups will need to be assessed and compared before the results of the trial can be reported. Please remain patient as the investigators conducting the trial are proceeding as fast as possible.

Get Involved

The Myositis Association strives to provide quality services, improve the lives of myositis patients, find better treatments and, ultimately, a cure for these devastating diseases. Thanks to you, when myositis patients have nowhere else to turn, The Myositis Association is there to help. You can help support TMA in the following ways.

[Become a member of The Myositis Association.](#) By joining TMA, you not only receive the many benefits of membership - you make a difference! Your membership adds to the growing number of patients, family members and friends who help fight for more awareness and more funding for research. Please be a partner in this important work.

[Make a donation to TMA,](#) in whatever amount is comfortable for you. Every dollar counts toward the goals of reaching out to everyone affected by myositis; educating and supporting patients, families and physicians; and finding a cure. There are many ways to contribute to TMA.

[By volunteering your time and talents,](#) you give a priceless gift to all myositis patients. Register your volunteer interests and skills with TMA and you will be contacted when volunteer opportunities arise.

[Advocate on behalf of myositis patients.](#) Contact local media, hold an awareness event, or call your legislators to inform the public about myositis and the need for more myositis research.