



THE MYOSITIS ASSOCIATION

KEEP IN TOUCH

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

April 2014

SPECIAL EVENTS

- Future meetings from 1:00 pm–4:00 pm on **April 5th, July 26th, and November 14th**
 - Meeting at Our Lady of the Fields Catholic Church 1070 Cecil Ave. S, Millersville, MD 21108
 - Directions call Bitsy Anderson 410-987-8407 or terrybitsy@verizon.net
- FYI**
- **2014 Annual Patient Conference** will be in Reno, Nevada, **September 4-7, 2014**
 - Go on the TMA website (www.myositis.org) to get the latest on ;

1. Details about the 2014 Patient Conference in Reno, Nevada.
2. Navartis has received a breakthrough status on a drug for IBM.
3. Acthar—now available as a treatment for Dermatomyositis and Polymyositis.
4. Veterans Issues
5. Great Videos on Fall Prevention and Dysphagia

RUN,WALK,ROLL FOR A CURE

1. Our next RUN, WALK, ROLL is on **October 25, 2014** Centennial Park, Ellicott City, MD.

SYNOPSIS of our December 2013 Meeting

At our December 7th, 2013, meeting we had speakers- **Katie Norton**, Liaison to the Johns Hopkins Myositis Center and **V. Solomon**- Dermatomyositis patient and founder of the Chronic Illness Foundation of America (CIFA).

Katie Norton works in the Department of Neurology at Johns Hopkins Myositis Center. She is involved with fundraising and community outreach. Katie discussed current research being done at the center. She also can serve as a liaison between our group and The Myositis Clinic. More information about the Myositis Center can be found on their website at www.hopkinsmyositis.org. For more information about clinical trials, you may contact Kristen Riley who is the research coordinator. She can be reached at 410-955-8511. You can also visit www.clinicaltrials.gov to find out additional trials.



V. Solomon - is the founder of the Chronic Illness Foundation of America (CIFA). She is also an attorney. She began her story by explaining symptoms of extreme fatigue during her pregnancy. She became unable to lift her leg and her chin was filled with fluid. She started experiencing frequent falls which was thought to be sciatica due to pregnancy. Doctors stated that this was due to a hormonal imbalance. Speaking became very difficult and her voice started to change and she eventually became unable to speak. She went to the hospital where she was diagnosed with Polymyositis. Her cpk was extremely high and her organs were starting to fail. At that time, she was also tested for other diseases. She was then diagnosed with IBM when vacuoles were found to be present. She became unable to hold her infant son. Doctors had told her to prepare to be in a wheelchair in 5-10 years. Despite all this, she still assumed that she could still work. Her memory started to fail. She couldn't get out of bed and her eyes would shut and she couldn't open them. She then had an appointment with Dr. Mammen at the Johns Hopkins Myositis Center. He concluded that she actually had Dermatomyositis. At this point, her skin disease was very active. She had severe calcinosis and swallowing became



Member Input: What are some areas that you'd like to know more about? Please send any suggestions to Bitsy Anderson at terrybitsy@verizon.net or Jenny Leonard at jenny silverb@yahoo.com

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THE MYOSITIS ASSOCIATION

Created to provide support for patients and families. Provide communication between medical advisory board, general medical and patient communities and increase funding to support research.

very difficult. She tried many different drugs for treatment such as Rutuxin, Solum Medrol, CellCept, and Methotrexate. She had a three year fight in order to be able to get the Rutuxin. This is while being employed at a Fortune 500 company which supposedly provided good benefits. She was put on extremely high doses of steroids. In addition to the Solum Medrol, she was prescribed 90 mg of oral steroids. One of the most difficult side effects was psychosis from the steroids. She has many gaps in her memory and she became very paranoid. After all of her experiences with her illness, she now realizes **it is very importance to interview your providers to make sure that they are well versed in Myositis.** Today, it has been 5 years February since her last severe flare and her flares become less and less debilitating. She has realized that **it is important to not overdue yourself.** She now knows that it is important for her to **live an even keeled life.** Her illness showed her that people with illness **should not have to be alone in the fight against their illness.**

She now feels that her purpose in life has changed. She founded CIFA, Chronic Illness Foundation of America, in 2012. The organization gives an integrative approach to dealing with disease. The organization provides people with information about knowing their rights, planning for life, important documents, as well as support groups. "The organization aims to address the health needs of communities by raising awareness and providing practicals on how to prevent common illnesses; and to be the voice of the community, bringing amazing and inspirational stories from those who have learned how to **thrive and not just survive** with conditions that have no cure." For more information visit: <http://www.cifa-usa.org>.

WHAT EVERY VETERAN WITH MYOSITIS SHOULD KNOW

- You do not need a "service connected disability" to receive health benefits from the VA.
- Your current health insurance does not affect your eligibility for VA healthcare, but a co-pay will be billed to your health insurance for non-service-connected conditions. However, the VA cannot bill an HMO for co-pays.
- While some veterans qualify for cost-free health care services based on qualifying factors, most are required to complete an annual financial assessment (sometimes called a means test) to determine whether they qualify for free services.
- VA funds appropriated by Congress each year are limited, so the VA has established priority groups to make sure certain groups of veterans are able to enroll before others. Once you are enrolled and your eligibility verified, you will be assigned to a priority group. The priority groups range from 1 to 8, with 1 being the highest priority. Some veterans may have to agree to pay a co-pay to be placed in certain priority groups. Find more information on priority groups go to: http://www.va.gov/healthbenefits/resources/priority_groups.asp.
- There are benefits granted to veterans who were exposed to Agent Orange. Exposure sites include Vietnam, Korea DMZ, Thailand Military Bases, and tests and storage outside Vietnam. Find information on Agent-Orange related diseases, benefits, exposure locations and provider resources. <http://www.publichealth.va.gov/exposures/agentorange>.

COURAGE IS BEING AFRAID BUT GOING ON ANYWAY...Dan Rather

Thank you to all who attended the November meeting!! It is so great spending time with you.

Now we need help with the Myositis 5K Run, Walk, Roll on October 25th.

Everyone can help, pick one or several

- **Encourage all your friends to register or donate**
- **Send emails, post on face book the details, get your children to help that day or by contacting sponsors,**
- **Come to our meeting on April 5th and see where the biggest need is. With you it can be a BIG success.**

