

TMA TN Myositis Support Group

TN MYOSITIS GROUP Newsletter

May 31, 2021



1st TMA TN Myositis Support Group in Nashville,
Tn., MAY MYOSITIS AWARENESS MONTH

Hello!


Welcome to our first TN Myositis Support Group Newsletter,

We would like to first give thanks to all who have been a part of our TN Myositis Group; it wouldn't be a group without you, the main Ingredients. Thank you for all of your help and support. We would like to also thank all of you who came to our meetings for the past 2 years.

Special thanks to Governor Bill Lee, Mayor John Cooper, and Mayor David Briley, and Joseph Williams,(Governor Lee's Director of External Affairs). Thanks to Yolanda Pointer and family, all of our Guest Speakers, Surprise Speakers, and the Staff at TMA. Some of our TMA Staff is no longer with us, they have moved on to greater endeavors and some much needed R & R; they are very much missed.

Thanks to Dr. Rex Bickers(TMA Board Member), Dr. Jennifer Young(Vanderbilt University Rheumatologist), Senator Brenda Gilmore, Melissa Giavoni(Balance Nutrition Counseling), Michelle Vogel(CSI Pharmaceutical), Ms. Ward, Mary McGowan, Khaleelah Cohen, LaDonna Johnson, Tricha Shivas, Laurie Boyer, Carla Sparkler, Cheryle Miller, Elizabeth Garrick, Schalonda Spivey (TN Group Members), Randy Heinig, Marianne Moyer, Bill Simeral, and our TMA's Original Women of Color Panel, which includes Kaniah Gunter, Holly Jones, Elisa Glass, Dale Scott, Christine Peart, Linda Shaw, Portia Wilson, Sharon Mills, Yvonne Bernard, Darlene Carruthers-Shelton. We had so much fun at our meetings, sharing our stories, our strengths and struggles Laughing, crying and just having that time to fellowship together, being able to see one another. Covid -19 physically kept us apart but we virtually connected. How awesome is that!!!

There was a lot going on in the month of May across every city, state, and country to raise awareness about this rare autoimmune disease called Myositis. The Myositis Association hosted their 2021 Virtual Patient Summit, which was packed with so much information about all the different types of Myositis(Polymyositis, Dermatomyositis, Inclusion Body Myositis, and Juvenile Myositis). There were breakout sessions, Professional speakers and also Kit Support Group Leaders who were able to speak.



Unfortunately I was unable to attend this year. The day after Mothers Day, I was hospitalized with a cpk of 17,000 and hence my absence from the meeting.

My levels run anywhere from 8,100-200,000. CPK stands for Creatine Phosphokinase. The higher the cpk levels the more danger it becomes for a person's life. This happens because as the muscles break down, the muscle enzymes are released into the body and can block the kidneys causing Renal Failure, weakening of the muscles, affecting all the extremities closest to the trunk of the body. I, like so many others, also experience having everything coming back normal, negative. Even if a doctor's numerical range is normal to them, for me it isn't, especially if I am hurting, in excruciating pain, and having trouble walking, getting up, or it's too painful to sit down. As we know, this disease is harder to diagnose in some people than others. And too, this disease is very fatal especially for Women of Color, more fatal than any other race.

Our TN Group has many members and a lot of them are in remission!!! We celebrate you everyday. We who are still either waiting for a proper diagnosis or waiting for some kind of treatment to relieve our suffering so we can manage our life on a daily basis have hope. We Pray that one day soon we will be in remission too.

Embracing this new way of living can be a challenge, but it is very necessary to move forward and to enjoy what life we have now. Helping others keeps our mind off of what we are going through; being that voice to encourage someone else or even being that person's listening ear means so very much. It helps each of us to adapt to a new way of living, a new and smarter way of doing our day to day tasks.

To our members, if you would like to have any of your stories read, have recipes that you make that are healthy and can help with inflammation, for the overall body to become healthy, poems, or to have your own column of your thoughts, we would love to hear from you, as we love and enjoy group participation.

Email them to our group email address, at: rare.unique2gether@gmail.com

If you would like to know more about Myositis and would like to become a member of TMA to volunteer in anyway you can, go to tma's website at : www.myositis.org

We will have a meeting coming up soon. You will be notified of the date and time; put your thinking caps on! Our Community is always welcome to join us. We look forward to seeing you!

Darlene Carruthers-Shelton

TN Myositis Support Group Leader

WE ARE STRONGER TOGETHER THAN ALONE! WE ARE A MYOSITIS FAMILY



