May, 2023

Issue 3

TMA MYOSITIS SUPPORT GROUP

Maryland, Delaware,
Washington DC, and
Northern Virginia
Connected by Myositis and
the Chesapeake Bay!

Support Group News

HELLO THERE!

Greetings from Jenna and Bitsy!

We hope everyone is enjoying the wonderful weather of this time of year!

On May 20th TMA hosted its virtual summit and we have posted short recaps about what we learned from several of the presentations. If you have any questions or need further clarification you can email chesapeakemyositis@gmail.com.

HEART HEALTH AND MYOSITIS by Julie Paik, MD, MHS at Johns Hopkins University School of Medicine

Dr. Julie Paik, who addressed our group in our last April meeting, was one of the first to present at the virtual summit, she spoke about heart health in myositis patients. In your body the heart is a muscle and can be affected by the same process of inflammation that affects skeletal muscles. While heart inflammation in myositis is rare, it can happen. The anti mitochondrial antibody is associated with severe heart disease in myositis. There is an increased risk of myocarditis, but not of stroke associated with myositis. The highest risk of myocarditis is within the first year of a diagnosis of myositis. It is good to know that your Troponin T levels (a typical measurement of heart health doctors use to determine if there is heart damage) can be elevated with myositis and it does not mean there is heart damage if your Troponin T levels are elevated. The Troponin T levels are elevated in 41-78% of myositis patients because it is falsely registering inflammation in skeletal muscles. If you have a doctor tell you that you may have heart damage because of Troponin T levels, you should inform them of your myositis diagnosis and request additional testing.

FYI

FACEBOOK
MYOSITIS SUPPORT GROUP - DC, MD, DE, & NO.VA GROUP

YOU TUBE
- JERRY KING IBM'ERS

CLINICALTRIALS.GOV

ANNUAL 2023 INTERNATIONAL PATIENT CONFERENCE IN SAN DIEGO, CA
SEPTEMBER 7 TH – 10 TH
GO TO WWW.MYOSITIS.ORG FOR MORE INFORMATION

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EXERCISE AS MEDICINE by Helene Alexanderson, PhD at Karolinska University Hospital

Exercise is an important part of treatment to improve muscle function and is safe and can reduce inflammation in all types of Myositis. It is very important to acquire the guidance of a Physical Therapist (familiar with Myositis or one willing to talk to an expert) before engaging in an exercise program. Exercise can improve muscle strength., can improve muscle endurance and aerobic capacity., might reduce fatigue., might reduce CK levels, lead to no increase of inflammation in muscles., and starting to exercise early right after diagnoses leads to a more physically active lifestyle. It is a good idea to start in lower level of intensity and adapt to your levels of pain and fatigue. It proves to be beneficial to accomplish shorter sessions of exercise more frequently. Gradually build up to your goal. Set short term and long term goals. When you find activities, you enjoy the rate of success is better. Listen to your body. Some good times of exercise include: warm pool, Tai Chi, breathing/ mindfullness, relaxation, singing, & balance. Doing something is better than doing nothing.

Understanding and Managing Your Stress Response by Natasha D'Arcangelo, QS, LMHC, NCC, CCTP, CCFP at Headspace Health

Natasha D'Arcangelo spoke to the summit about working to manage your stress response. The first thing she asked was "Are you 100% safe right now?", she asked this question with the purpose of trying to reframe our thought about the causes and the beliefs about those causes of stress. When asking if we felt safe right now, she was trying to help us reframe what is a real vs. what is a perceived threat. Our body reacts to both of these in the exact same way and by getting our body to calm down, for even just five seconds, can help our bodies find moments of relief when experiencing chronic pain. Using self regulation tools, such as diaphragmatic breathing, the wet noodle, and a muscle to skeleton exercise helps people become aware of what their body is doing in that exact moment, and can receive stress that we may not even be aware of. Ms. D'Arcangelo recommended two books on this topic:,*The Body Keeps The Score* and *What Happened To You,* in order to help us manage our stress responses better in the future

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Mental Health & Myositis by Christopher Graham at University of Strathclyde

There is not much research in this area. There are more studies on Quality of Life which is reduced over time by physical health, ability, and emotional stress. Quality of Life varies between individuals with MYOSITIS. Some live well with Myositis but Myositis symptoms can cause additional challenges to an individual's mental health. Areas that are impacted by Myositis are muscle weakness, pain, fatigue, changes in movement, changes in appearance, embarrassment and anxiety may get worse. Psychological interventions help people understand or to change what they do or how they do it, different therapies target different psychological processes (beliefs, insights, emotions, regulations, coping and relationships.), and the goal is to improve a given outcome, such as adjustment, mood, well-being. Today this intervention can be carried out through individual therapy, group therapy or apps and books. One such intervention is ACT- Acceptance and Commitment Therapy. This is in the broad school of Cognitive Behavior Therapy. This aims to engender a quality called Psychological Flexibility, which involves living well as opposed to feeling less bad. An individual might develop their psychological flexibility by connecting with the qualities you want to show in your life. They may consistently do things in ways that reflect those values and choose to do things that make life bigger. Look at the smallest single step you can take to get you back on track. Reflect on "is what I am doing working". Some resources that were recommended were: Facing the Storm – Ray Owen, The Happiness Trap – Russ Harris, and Mindfulness for Health – Vidyamala Burch.

Myositis: Staying on top of your illness and finding your voice by Shawna Nielsen, BSN aTMA Community Member

Shawna Nielsen, BSN and dermatomyositis patient spoke at the summit about how to navigate doctors offices and care teams. When described a support team, she said that the patient is always the most important team member, but other members may include, family, friends, support groups, doctors, nurses, or anyone else helping you on your myositis journey. A care team is comprised of a home team and an away team. The home team is anyone that lives in your area and you have regular access to, this may include friends physical therapist, a primary care doctor, or anyone else in your area. The away team comprises of anyone you travel to see, this may include specialist doctors, family that are far away, etc.

Ms. Nielsen went on to talk about how to prepare for doctors offices, this includes having paper copies of all lab reports, documents, and notes from previous doctors. You should also make sure to properly communicate with your provider about what your goals are and how you hope for them to help you achieve those goals. The other topic of conversation went to mental health, how after diagnosis many patients do not take the time to properly grieve. How grief from a diagnosis is natural and giving yourself that time (without falling into a pity party) can help you find your way to acceptance and make the most out of what you do have in life.

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Nutrition & Myositis by Kaniah Gunter at Unique Guidance Nutritional Health Coaching, LLC

Kaniah Gunter spoke about proper nutrition in myositis patients. She started out by saying that everyone has their own bio-individuality; what works for one person may not work for another. Everyday we make dozens of lifestyle choices that contribute to our health, it is our responsibility to make the most of those choices. Ms. Gunter spoke of the primary foods that nourish someone: feelings of love, worth, intimacy. These primary foods give our body serotonin and dopamine, which help our bodies function properly.

Once she was done with this she went more into nutrition and how to build one's relationship with food. This conversation started by asking "What is your Why?" "Why do you want to change and build a new relationship with food?". Everyone has different goals when it comes to nutrition and knowing your "Why" will help you set healthy and achievable goals. These goals can help be achieved by journaling and practicing weekly meal prep (which also helps save time and money). Ms. Gunter said that preservatives, additives, and sugar cause inflammation in the body and should be avoided in myositis patients. We should also try to avoid all the "middle aisles" at the grocery store, the ones that has all the food coming in a pre-packaged box. Sticking the to sides of the grocery store helps ensure there are less preservatives in the food that you eat. It also helps to ensure that good veggies take up half of your plate at meal times. A good anti-inflammatory diet includes eating plenty of plants (the more colorful the plants the more antioxidants are in them). Ginger is good for treating sore muscles and turmeric has many benefits as well for the body. An anti inflammatory diet also includes avoiding red meat, which is known to cause inflammation in the body.

Ms. Gunter also made sure to remind us that drinking plenty of water (6-8 glasses a day) will help improve gut health. The health of the gut impacts many other systems in the body. As patients with an auto-immune disease, she wanted us to be aware that most immune cells have vitamin D receptors, so we should be sure to take plenty of vitamins.

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Upcoming Meeting Information

Our next meeting will be held on June 17th at 1 pm to discuss Sharing your Success and Challenges. The entire meeting will be dedicated to discussion between myositis patients. Sharing each others highs and lows, talking about resources that can be beneficial to other patients. Our meetings are a place of support, care, and love between myositis patients. We are going to be taking the entire meeting to helping each other cope with our disease. There will be whole group discussion as well as breakout group discussion for each individual disease and a caregiver group. Come prepared to talk, listen, and further your myositis journey.