



**Southern Arizona Keep In Touch (KIT) Myositis Support Group**

Volume 1, Issue 3

This is the third edition of a more-or-less quarterly newsletter that is intended to provide you some information related to myositis, with emphasis on Southern Arizona resources. We gather it from many different sources and point you to these locations to help you continue researching those items that interest you. We will also include a summary of the notes from the previous quarter's support group meeting. We hope to give you some ideas, pose some questions, make you think, and help you as you live each day (or are a caregiver for someone) with any of the myositis family of chronic illnesses.

Vickie Jahaske & Rosemary Badian

Please provide feedback and comments, plus ideas for future newsletters to:

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Upcoming meetings (from 1:00-3:00 pm Arizona Time, either via Zoom, or at the DIRECT Center for Independence, 1001 N Alvernon Way, Tucson) are:

Friday, August 14, 2020 PST  
Friday, November 13, 2020 MST

A decision will be made before the next meeting whether it will be a combination of in-person and Zoom, or strictly via Zoom. A meeting notice with a Zoom link will be sent out prior to each meeting.

The Arizona/Southwest TMA KIT group met via Zoom on Thursday, May 7, 2020, from 1-3 pm. Fifteen people attended at least some of the meeting – fourteen who have some form of myositis, and one spouse/caregiver. We went around the group, with new attendees discussing their myositis history, while prior attendees discussed what has changed in their health since the previous meeting. We also enjoyed sharing positive changes in our lives since the start of the COVID-19 pandemic. This is a summary of status and potentially helpful ideas, with names withheld in the interest of privacy of the attendees.

### Person 1 – (JDM)

- Diagnosed in her early 20s and has had the disease all her adult life.
- She reminded everyone that May is Myositis Awareness Month, and she said that every year she does a Facebook post to remind her family and friends about Myositis.
- She showed us her Hizentra, which is sub-Q immunoglobulin medication. She administers it to herself once a week – it takes about 1.5 hours, uses tiny needles, and has no side effects. She rotates where she gives herself the injection between four locations, which avoids bruising in any one area. She has been on cortisone for 30 years, and the Hizentra has allowed her to lower her cortisone dosage to every other day. She has a prescription for Pain-Eze spray, which is a prescription anesthetic, in case it is needed to numb skin before needle insertion. This can be used for many procedures: <https://www.gebauer.com/painease>
- She is positive about quarantine as she has added many new things to her routine, including yoga, water coloring and an on-line writing class.

When you find out your normal daily lifestyle is called “quarantine”



### Person 2 – (sIBM)

- He tried the Ankle and Foot Orthoses (AFO) braces he mentioned last meeting, but they didn't work well for him.
- He is staying in touch with family and friends by phone during the pandemic shutdown and is spending his time reading and on his computer.

### Person 3 – (DM)

- His health is currently pretty good.
- Quarantine hasn't been too bad for him, although he misses going to the store and seeing family.
- He enjoys hobbies of painting and container gardening.

### Person 4 – (sIBM)

- He is doing OK with the quarantine except for missing physical therapy at the gym.
- He has plenty of projects, so he isn't bored – but he does miss going to the store and seeing his grandkids.

### Persons 5 & 6 – (Statin Induced Necrotizing Autoimmune Myopathy (NAM) & spouse/caregiver.)

- He was put on Artorvastatin, which they believe caused his illness.
- His symptoms started 2 months after his statin dosage was increased.
- He has been getting IVIG for 4 months without side effects. It is helping him be more mobile so he can do more and requires less care.

### Person 7 – (sIBM)

- He is doing well and takes one day at a time - he is thankful for every day.
- He had many life-threatening health problems in 2019 – he lost a leg and two toes on his other foot.
- The quarantine isn't bothering him; and in fact, he's seeing his kids more than before on Zoom.

### Person 8 – (sIBM)

- He has Ankle Foot Orthotics (AFOs), and initially they required many adjustments. He hasn't had to have them adjusted in 2-3 years, and they help him have mobility.
- He has an all-terrain rollator, and can go around his ½ acre using that.
- With his AFOs, he is able to walk without a cane.
- During the pandemic he has missed seeing his grandchildren, but he has been decluttering and exercising more.
- He thanked his wife for her caregiving and sticking with him for so many difficult years.

### Person 9 – (sIBM)

- She finds that exercise helps, so she walks and does PT.
- She has a Cubii exercise pedal machine but finds she is weaker after exercise (others also resonated with this).

### Person 10 – (sIBM)

- She recently completed a move to an independent living community due to her sIBM.
- She has been suffering with side effects from high blood pressure medication. Others commented that high BP has been helped by juicing celery, plus taking Nat Mur (Natrum Muriaticum), which is a natural salt that helps adrenals.
- She stressed that we each must be our own advocate and must keep good records of our bloodwork and treatments.
- She is a gym instructor who teaches balance classes through The Brain Gym. <https://breakthroughsinternational.org/programs/the-brain-gym-program/>

### Person 11 – (DM and myasthenia gravis)

- She has been off work as a nurse since August 2016. She and her husband also dealt with a home with black mold.
- She gets IVIG at home and deals with side effects from different brands (note – others have previously commented that different brands affect them in different ways).
- She also takes Benlysta (a biologic therapy) which appears to help.

### Person 12 – (PM/DM)

- She exercises every day, but has learned to listen to her body and rest when needed. She does stretching periodically throughout the day.
- Her main issue right now is her feet – it hurts her heels to walk. There were a few suggestions people in the meeting made: 1) find a chiropractor who knows feet; 2) try reflexology; 3) try Vi Peel, which is a body exfoliator – use it to scrub your feet once a week in the shower, then hydrate your feet well.
- She recommends this website for people facing health challenges: <https://themighty.com/>
- During the pandemic she is doing more baking, doing exercise classes on line, meditating more and becoming more tech savvy. She misses getting hugs from her grandkids.

### Person 13 – (DM with Interstitial Lung Disease (ILD) and Raynaud's.)

- She has been participating in a Phase 3 drug trial (based out of Phoenix) for Lenabasum since September 2019. Here is more information on the drug trial <https://clinicaltrials.gov/ct2/show/NCT03813160>.
- Since early November she has been feeling much better – not sure if it is the drug trial or just the DM cycling. She doesn't know if she is getting the placebo or the drug, but starting in Sept 2020 she has signed up for the Open Label Extension, which means she is guaranteed to get the drug for another year.
- At the start of the pandemic, she and her husband talked about what lifestyle changes they wanted to make. They used this impetus to reinvent their lifestyles a little. They have been getting up earlier, exercising more, walking more, trying new recipes, and eating their main meal in the middle of the day.

### Person 14 – (IN/DM)

- She took prednisone and antibiotics and went into remission, but now controls her DM through alternative therapies including homeopathy, juicing, meditation and Tai Chi. Be aware that homeopathy is tailored for each individual based on their symptoms and characteristics. Find a knowledgeable alternative practitioner.
- She finds this helpful for foot pain: <https://www.homedics.com/shiatsu-elite-foot-massager-with-heat.html>
- She shared this link about activating energy: <https://youtu.be/kaefdiE4ovk>

### Person 15 – (sIBM)

- She manages her energy level carefully. She's enjoying gardening.
- Her big news is a new power wheelchair providing freedom to take spins around neighborhood. She got a new cushion (the other one was faulty) and has had it readjusted to her body - all the fine tuning helps. It takes a while to figure it all out (adjustment wise and driving wise) and there is a definite learning curve.

All people who have myositis or are caregivers for those with myositis are invited to attend the KIT meetings, either in person or via Zoom. The meetings provide a supportive environment with people who truly understand, to share fears, concerns, ideas and success stories.

Beyond our local level of myositis support, all are encouraged to be registered as a member with The Myositis Association ([www.myositis.org](http://www.myositis.org)) to take advantage of their many excellent member benefits. TMA's mission is to improve the lives of persons affected by myositis, fund innovative research and increase myositis awareness and advocacy. Becoming a member is without cost and will ensure you receive by mail the well-done quarterly TMA publication, The OutLook, with the latest news on treatment, coping skills, resources and research.

TMA envisions a world without myositis.

## **News of potential interest:**

### General health, exercise and nutrition:

- Foods to help autoimmune diseases:  
<https://www.cleaneatingmag.com/clean-diet/eat-to-beat-autoimmune-diseases>
- Nutrition tips for Myositis patients:  
[https://www.hss.edu/conditions\\_nutrition-and-myositis.asp](https://www.hss.edu/conditions_nutrition-and-myositis.asp)
- Natural support for autoimmune and inflammatory diseases:  
<https://restorativemedicine.org/journal/natural-support-for-autoimmune-and-inflammatory-disease/>
- Activation of autoimmunity following use of some herbal supplements:  
<https://pubmed.ncbi.nlm.nih.gov/15210464/>
- Exercise safe for patients with myositis:  
<https://www.healio.com/rheumatology/polymyositis/news/online/%7Bd30c318f-ff13-4fa0-aeb6-92b16ae2400a%7D/exercise-safe-for-patients-with-myositis>

### Autoimmune specific news:

- Explaining myositis to friends and family:  
<https://understandingmyositis.org/explaining-myositis/>
- Rogue cells at root of autoimmune diseases:  
<https://apple.news/AvqgvifsdTG6W5VmX4ptZpA>
- Multiple sclerosis research looks promising:  
[https://theheartysoul.com/cambridge-scientist-on-verge-of-curing-multiple-sclerosis/?utm\\_source=STFD&fbclid=IwAR2\\_saG-IPhOm1Jnlbavm9mp9Jq5d5ZBDs9YjQILVbO4NiAWQypmwSX7iuM](https://theheartysoul.com/cambridge-scientist-on-verge-of-curing-multiple-sclerosis/?utm_source=STFD&fbclid=IwAR2_saG-IPhOm1Jnlbavm9mp9Jq5d5ZBDs9YjQILVbO4NiAWQypmwSX7iuM)
- Side effects of methotrexate:  
<https://www.usnews.com/news/health-news/articles/2020-02-18/study-probes-side-effects-of-methotrexate-used-for-psoriasis-rheumatoid-arthritis>
- Chronic Fibrosing Interstitial Lung Disease treatment approved:  
[https://www.boehringer-ingelheim.us/press-release/fda-approves-ofev-first-treatment-chronic-fibrosing-ilds-progressive-phenotype?fbclid=IwAR3oEFNMVtzldGqyA\\_Vyc31T7oxYfSL1cF\\_MI3jYQuCjRrOxflHUJCS56U8](https://www.boehringer-ingelheim.us/press-release/fda-approves-ofev-first-treatment-chronic-fibrosing-ilds-progressive-phenotype?fbclid=IwAR3oEFNMVtzldGqyA_Vyc31T7oxYfSL1cF_MI3jYQuCjRrOxflHUJCS56U8)

### Drug trial information:

[www.clinicaltrials.gov](http://www.clinicaltrials.gov) (this is a useful site – search on Myositis)

- Trial to Evaluate the Efficacy and Safety of Abatacept subcutaneous (SC) in Combination with Standard Therapy, Compared to Standard Therapy Alone in Improving Disease Activity in Adults with Active Idiopathic Inflammatory Myopathy  
<https://clinicaltrials.gov/ct2/show/NCT02971683>
  - Trial to Evaluate Efficacy and Safety of Lenabasum in Dermatomyositis <https://clinicaltrials.gov/ct2/show/NCT03813160>
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## Helpful Resources:

- Links to the TMA Annual Conference videos are available here: <https://www.myositis.org/myositis-library/presentations/>
- Some useful TMA exercise videos are available here: <https://www.myositis.org/about-myositis/treatment-disease-management/exercise-physical-therapy/exercise-videos/>
- A resource to help find potentially lower cost medications: <https://www.goodrx.com/>

## **Recipes and Jokes Corner**

Just in time for summer -

### **Immune-boosting Green Smoothie (makes 1 large serving):**

(Adapted from <https://www.gimmesomeoven.com/post-workout-green-smoothie/>)

#### **INGREDIENTS –**

- 1 banana, peeled and cut into chunks
- 1” piece of ginger root, peeled and coarsely chopped
- 1 cup of fresh spinach
- 1 cup frozen or canned pineapple chunks
- ½ cup shredded or sliced carrots
- ½ cup plain yogurt of choice (dairy or non-dairy)
- ½ cup milk of choice (dairy or non-dairy)
- 2 Tbsp protein powder of choice (optional)
- 1 Tbsp chia seeds

#### **INSTRUCTIONS –**

1. Add all ingredients to a blender, blend well, serve topped with more chia seeds if desired

To make you smile:

How do trees access the internet?

They log In.

Why do nurses always bring red crayons to work?

In case they need to draw blood.

What do you call two Banana Peels?

A pair of slippers.

Giraffes can grow up to 14 feet

However most just have four.

Someone told me they really like my name.

I said "thanks, I got it for my birthday!".

What's the weakest part of a car?

The nut holding the steering wheel.

Why don't ants get sick?

Because they have little anty bodies.