



Southern Arizona Keep In Touch (KIT) Myositis Support Group

Volume 1, Issue 4

This is the fourth 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 meeting (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, 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 Friday, August 14, 2020, from 1-3 pm. Nine people attended the meeting.

We went around the group, with new attendees summarizing their myositis history, while prior attendees discussed what has changed in their health since the previous meeting. This is a summary of some potentially helpful ideas that were discussed during the meeting. Before you consider any changes to treatment, please consult with your own medical doctor about its safety. TMA does not endorse any modalities mentioned here.

The TMA regional KIT group leader started the meeting by talking about TMA. She mentioned the upcoming Annual Conference, which costs \$95 to attend, and is a virtual meeting September 11-13. Peter Frampton was just announced as the Keynote Speaker. If you are unable to participate, many of the meeting presentations and handouts will be available at the TMA website after the conference.

<https://www.myositis.org/myositis-library/annual-patient-conference/>

Reported Helpful Treatments and Activities:

We are reminded to be our own best advocate. Pay attention to what happens in your body after each med change, even two months later. Keep a journal. Set small goals and hang on to the next one. An inspiring sign of progress is to have more good days than bad days. One new member realized a need for more emphasis on exercising, not just walking. Every human needs to exercise, myositis or not. Some concentrate on diet, exercise and supplements resulting in less brain fog and more energy.

Physical Therapy and Exercise: PT has helped many of the meeting attendees, including and especially water therapy. If you try PT and it doesn't work well, find a different therapist and try again. The first PT and then OT places one tried did not help, but the third place did. One member with DM is doing PT this summer with a great therapist who has helped her work on her feet and ankles. The therapist helped her realize that she has very tight feet, walks with her feet pointing out and her toes bent--all of which affects her balance. She has started doing new exercises that have helped her a lot. She is finally able to walk barefoot, which is great progress.

Another with sIBM does pool therapy two days a week and land therapy one day a week. She really feels the exercises have been

wonderful for all muscle groups and has helped her feet and ankles a lot. She was able to drive to PT, which is a huge improvement.

One of our members, Laura, teaches balance classes through The Brain Gym. Laura is currently teaching classes on-line on Wednesday at 1:00 pm MST. Anyone who is interested in participating should email Laura at sedonabalance@gmail.com, and she will send you a Zoom meeting invitation. Laura stated that people who do the Brain Gym activities have a 20% reduction in their medical costs and a 66% reduction in falls. You can learn more about Brain Gym at <https://breakthroughsinternational.org/programs/the-brain-gym-program/>. Laura will be presenting a fall prevention workshop at the upcoming TMA conference.

Lenabasum Drug Trial: One of our members has been participating in a Phase 3 drug trial (based out of Phoenix) for Lenabasum since September 2019. Since late October/early November 2019 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.

Immune Globulins: One of our recently diagnosed members with DM began Privigen IVIG, but even though it has helped her, she has had some very bad side effects (erratic heartrate, low pulse), and last time ended up in the ER twice. Another continues to report good success with SubQ IG, Hizentra, which she administers to herself at home.

Low Dose Naltrexone (LDN): Some report increased energy and being able to function more normally while taking LDN. It is usually prescribed by a naturopath or Functional Medicine doctor, although one member has a rheumatologist prescribing it. It is an Rx filled through a compounding pharmacy. You can learn more about it at <https://www.lowdosenaltrexone.org/> and <https://ldnresearchtrust.org/>.

Reported Helpful Aids/Modifications:

- Medical experts say you should get an adaptive device before you really need it to prepare for future needs.
- Ankle Foot Orthotics (AFOs) help some to walk on flat surfaces, with the aid of a cane.
- One member uses an all-terrain rollator, and can go around outside a ½ acre property.
- Household modifications that have helped include raised toilets, removed the steps, a vertical lift from the carport to the house, and a stair climber chair.
- It can be difficult to accept, but several falls and broken bones has one IBM member no longer walking. A personal aide now helps with bathing and grooming. He has a power wheelchair from Spinlife <http://www.spinlife.com/>, and their support people have been very helpful to him. He has gained some independence by getting a handicapped van.
- A member shared these resources for equipment: In Phoenix for donated equipment - Helping Hands Arizona. There is also one in Yuma at www.helpingyuma.org. Also in Phoenix, White Dove Thrift Shop, 5035 N. 7th Ave (602-776-1540) has a warehouse in the back where they loan all kinds of medical equipment. This is actually where her friend got his upwalker.
- Foot massager from Core Products proved helpful for one member: <https://amazon.com/Core-Products-Jeanie-Variable-Massager/dp/B00PSTP9QS/ref>. She then went to the Core products website and bought a stand to put it in, so she can use it on her feet.

Digestion Discussion: The subject of digestion and constipation was raised. Some have had issues with swallowing. This was a good reminder to see a GI specialist to make sure nothing is seriously wrong.

Several people had digestive ailments helped by the following:

- Glutamine powder, added to juice once a day (<https://amazon.com/gp/product/B001HITON8/>)
- Aloe vera juice (any brand of pure juice) - 2 Tbsp/day
- A good probiotic (there are many available)
- A digestive enzyme before meals with hard to digest foods (<https://www.amazon.com/gp/product/B000GG5K3U/>)

--One went to a naturopath and is now taking the following to help her digestion:

<https://amazon.com/American-Health-Chewable-Potency-Tablets/dp/B01MRQG8G3/ref> (when in a restaurant)

<https://amazon.com/AbsorbAid-Digestion-Stomach-Distress-Capsules/dp/B000VYXDIQ/ref> (a powder she takes at home)

--Another takes Garden of Life Omegazyme digestive enzymes with most meals: <https://www.allstarhealth.com/de.aspx?p=23026>

--Some in the group mentioned using intermittent fasting, which is eating during a smaller time window during the day (say from 10-5PM or 12-8 pm only) every day. The theory is this may tax the body less.

--Some do better eating their main meal in the middle of the day.

--Lack of activity will slow digestion.

--Remember to stay hydrated!

Stem Cell and PRP Treatments: *It is important to note that TMA's Medical Advisory Board cautions against the use of Stem Cell treatments. Until there is scientific evidence supporting the use of stem cells as a treatment for myositis, the potential risks outweigh the potential benefits.

<https://www.myositis.org/about-myositis/treatment-disease-management/can-stem-cells-cure-myositis/>

One member inquired about any experiences with stem cell treatments. One attendee said it is very expensive, but helped her when she tried it in 2015, until she had to take prednisone again which takes away stem cell benefits (of which she was unfortunately not aware). They saw others obtain really good results and believes the future of stem cell use for healing is increasingly hopeful.

Another member plans to start PRP (Platelet-Rich Plasma) injections next week. She is doing a series of four treatments once a week. During the treatment, they draw your blood, separate out the platelet-rich plasma, then reinject it into your body (in her case, on her thighs and back).

Human Connection: At this meeting we talked about a lack of empathy and bedside manner from some doctors. We discussed the idea of talking to doctors who have myositis patients about these TMA Keep In Touch support groups, as some find them very helpful. A book by Alan Alda was recommended: "If I Understood You, Would I Have This Look on My Face?: My Adventures in the Art and Science of Relating and Communicating". Human relation skills can be improved by all of us. One member was encouraged to share some improv exercises she learned for improving connection at our next meeting.

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) 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:

- Boost immunity through nutrition:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7308604/>
- Find a Plant-Based Practitioner near you:
<https://www.plantbaseddoctors.org/find>
- Recent research might help doctors understand lungs better:
<https://www.pressreleasepoint.com/yale-baylor-create-detailed-atlas-cellular-change-lungs-fibrosis>
- Reduction in blood flow to heart in Raynaud's patients:
<https://raynaudsnews.com/2016/12/02/reduced-blood-flow-in-heart-tissue-found-in-raynauds-patients>
- Zephyr valve aids breathing:
<http://med.stanford.edu/news/all-news/2020/05/valve-helps-emphysema-patients-breathe-easier.html>
- Yoga poses to improve balance:
<https://www.silversneakers.com/blog/yoga-seniors-poses-improve-balance/>
- Chair yoga for seniors (Adriene has many other good yoga practices):
<https://www.youtube.com/watch?v=-Ts01MC2mlo>

Autoimmune specific news:

- One way to treat Asthma and autoimmune diseases with diet:
<https://nutritionfacts.org/2020/06/16/one-way-to-treat-asthma-and-autoimmune-diseases-with-diet/>
- A fundraising effort to raise IBM awareness:
<https://www.singletonargus.com.au/story/6831930/kayaking-for-inclusion-body-myositis-ibm-awareness/>
- Service dog helps lady with IBM:
<https://blog.csipharmacy.com/patient-stories/service-dog-brings-more-than-self-sufficiency/>
- DM linked to sunburn episodes:
<https://www.medpagetoday.com/dermatology/generaldermatology/82148>
- Treatment idea for calcinosis associated with DM:
<https://onlinelibrary.wiley.com/doi/abs/10.1111/ced.14325>

Drug trial information:

www.clinicaltrials.gov (this is a useful site – search for Myositis)

- Trial to Evaluate the Efficacy, Safety and Pharmacokinetics of IgPro20 in adults with DM:
<https://clinicaltrials.gov/ct2/show/NCT04044690>
- Phase 2A Trial to evaluate PF-06823859 in DM Patients:
<https://clinicaltrials.gov/ct2/show/NCT03181893>
- IBM drug trial in Australia:
<https://www.notredame.edu.au/news-items/new-treatment-trial-for-rare-disease-offers-hope-to-thousands-of-sufferers-worldwide?fbclid=IwAR3roQkOX109fTzaoIxbKY99IvN0JJI3qSVZNvvpx4TkFJXSE0fWWiePCA>

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

A great vegan cheese sauce to use on veggies, mac & cheese, nachos... -

Vegan Cheese Sauce

Ingredients:

- 1 cup potatoes, peeled & diced
- 1/4 cup carrots, diced
- 1/4 cup onion, chopped
- 1 cup broth or water (divided)
- 1/2 cup raw cashews, (or 1/2 cup canned white beans)
- 4 Tbsp nutritional yeast flakes
- 1 Tbsp lemon juice
- 1 tsp salt
- 1/2 tsp garlic powder
- 1/2 tsp paprika
- 1/2 tsp mustard powder
- 1 pinch cayenne pepper, optional

Instructions:

1. If you are using cashews and do not have a high-speed blender, soak the cashews for a couple of hours or overnight. If you use beans or have a high-speed blender, you can skip this step.
2. In a large microwaveable glass container, place potatoes, carrots, and onion and about 1/2 cup water or broth. Microwave until veggies are soft. Cooking time will vary based on how small the veggies are diced.
3. When veggies are tender, drain and place them in a blender. NOTE: reserve 1/2 - 1 cup of the liquid from cooking the veggies. Add all the remaining ingredients, and start with 1/4-1/2 cup of broth. Blend until smooth, adding more broth if needed.

To make you smile:

What does garlic do when it gets too hot? It takes its cloves off!

You can never trust an atom... They make up everything.

Why do batteries feel lonely? Because they are never included in anything.

Who invented fractions? Henry the 1/8.

Why do green beans meditate? To find inner peas!

What did one hat say to another hat? You stay here I'll go on ahead.

Why don't crabs give to charity? Because they're shellfish!

I told my doctor that I broke my arm in 4 places. He said "Well, maybe stop going to those 4 places!"