



Southern Arizona Keep In Touch (KIT) Myositis Support Group

Volume 1, Issue 5

This is the fifth 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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The upcoming meeting schedule is (all are Saturdays):

February 13, 2021
May 8, 2021
August 14, 2021
November 13, 2021

All meetings will be via Zoom, from 1:00-3:00 AZ time (MST). Reminders will be sent to all AZ and Southwest region TMA members prior to each meeting.

The Arizona/Southwest TMA KIT group met via Zoom on Friday 13 November 2020, from 1-3 pm. Twelve people attended the meeting – two caregivers and ten people with either some form of myositis or anticipating a myositis diagnosis. Three of the meeting participants have DM, and seven either have IBM or are working towards an IBM diagnosis.

The TMA regional KIT group leader started the meeting by talking about TMA. She laid out the ground rules that TMA expects from meeting participants, which include being respectful and listening carefully, being non-judgmental, allowing support to be provided in a safe environment, expressing your own experiences but avoiding giving advice. She reminded the attendees that nobody is required to share their story, and listening is a gift. Members should focus on sharing and support. These reminders are good for all of us in many situations.

She mentioned the 2020 Annual TMA Conference, which was held virtually in September 2020. She attended, and said the meeting was very worthwhile. TMA hasn't released the meeting notes to the general public yet, but presentation materials from prior years' meetings are available at:

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

Here are some highlights and information that were shared.

Discussion About Treatments:

One of our members with DM has been participating in a Phase 3 trial for Lenabasum (from Corbus Pharmaceuticals) for 14 months. For the first year she didn't know if she was getting the actual drug or a placebo, but since late September she has definitely been getting the actual drug. Her health has improved dramatically over the past year, which she attributes to the Lenabasum. The Phase 3 trial has completed enrollment, so if all goes well the drug should be ready for FDA approval review by late 2021/early 2022.

Other discussion on medication for DM included one individual who was on methotrexate and steroids, but had horrible side effects to the point where she basically had no energy to move for 3 months. She switched doctors and is now taking Plaquenil and Cellcept, which has helped the rash on her hands subside – but she still has very low energy. One individual has been able to reduce her cortisone dose 75%, feels the best she has in five years,

has normal lab results, and attributes her improved health to weekly Hizentra infusions. The individual on Lenabasum has been able to stop her Cellcept after being on it for 3.5 years, and also has improved lab results.

The discussion on medications for IBM was shorter, as there is no identified root cause and there are currently no FDA approved medications for IBM. However, Arimoclomol is in a Phase 2/3 trial and Rapamycin showed some symptom improvements in a Phase 2 trial. Details about clinical trials related to IBM can be found at:

<https://cureibm.org/treatment/clinical-trials/>

One individual with IBM mentioned that he had tried Gabapentin, but the medication made him have more pain rather than less. One individual with DM also said that Gabapentin had caused her more pain.

Exercise and Other Potentially Helpful Tools/Aids:

Several people both with DM and IBM talked about how important exercise is for all of us. One individual with IBM reinforced that it is very important to keep the muscles you have through exercise. One individual with IBM said he is no longer driving because his hand strength is deteriorating, but he walks 1.5-2.5 miles every day using a walking stick. One individual with IBM has been doing autumn activities such as raking leaves, and uses his rollator to walk around his property. One person with IBM said he spends much of the day squeezing putty while he's sitting, to help retain hand strength.

Two aids that were discussed which provide hand exercise are hand-held exercise balls and hand putty (links to examples are below).

Exercise balls: <https://www.amazon.com/HPUP-Strength-Trainer-Therapy-Squishy/dp/B086WTNF4R/ref>

Hand putty: <https://www.amazon.com/Premium-Quality-Therapy-Putty-Exercise/dp/B01BLYNWIU/ref>

Several people mentioned that the best tool we all have is maintaining a positive attitude. Several attendees also discussed the importance of having a loving caregiver. One individual said that she had finally started counseling after many years with DM, and was now able to start grieving

the loss of her “normal life”, which was helping her attitude. “I have myositis, but I don’t let it have me,” is one admirable motto from an IBM sufferer. Try to stay in the present and try not to spiral down in depression was more helpful input from those of us in the trenches.

Doctors Familiar With Myositis:

Several doctors were mentioned who are very familiar with myositis.

- Dr Carolyn Bangert is a dermatologist in Tucson
- Dr Holli Horak and Dr Katalin Scherer are neurologists in Tucson
- Dr Todd Levine is a neurologist in Scottsdale

One individual who has symptoms like IBM and is trying to get a diagnosis has an appointment with a neurologist at Washington University in a few months – they are a well renowned institution for myositis.

Other tidbits:

We discussed adaptations people are making in their lives due to COVID. One important change many have made is getting groceries delivered (a couple of different services were mentioned). Everybody who has been taking advantage of this service seemed very happy with the results. Another suggested TMA’s website for articles about COVID, including videos by Dr. Rohit Aggarwal, Chair of TMA’s Medical Advisory Board.

One participant was concerned about the COVID safety of getting her teeth cleaned. Others reassured her that they had felt perfectly safe while at their dentists’ offices. One person mentioned a concern with the keyboard not being covered, and suggested to their dentist that they cover the keyboard with plastic wrap.

All people who have myositis or are caregivers for those with myositis are invited to attend the KIT meetings 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:

- Soy can have good health benefits:
https://www.pcrm.org/good-nutrition/nutrition-information/soy-and-health?fbclid=IwAR02kVUklvZE4wpDT4IQ6FeFMMvIEnT5bR4aIZyi2V9BnpP7L4xHSPqj_RM
- Good nutrition is anti-viral:
<https://medium.com/@mroswell/a-science-based-message-for-the-people-good-nutrition-is-antiviral-14a4528c7216>
- What happens when you eat too many carbohydrates:
<https://mariamindbodyhealth.com/happens-eat-many-carbohydrates/>
- How muscles really work – a cute and informative video:
<https://www.youtube.com/watch?v=Ktv-CaOt6UQ&fbclid=IwAR26pTXqFK9ez-bE2hpEChF2IOgRHp940qmLaSX88sjHqvK0Bcp44xWb2Bc>
- What to do if you get notification your disability benefits will be terminated:
<https://blog.csipharmacy.com/advocacy/disability-benefits-in-danger/>

Autoimmune specific news:

- Secondary causes of myositis – good summary of treatment options:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7538050/pdf/11940_2020_Article_646.pdf?fbclid=IwAR3vT-glt3dVefknYmPR932uFBWoyYop66Ccplgk1BdxDGHpOhL4EwPQP-A
- Encouraging news for people with lung disease:
https://medicalxpress.com/news/2020-09-druggable-pathway-lung-tissue.html?fbclid=IwAR3FLhdO2iAYJZdXppEWt3mkyRrWU7ISxO286hkrnT954_wxAJz9j8CKrOc
- New insights into understanding autoimmune diseases:
<https://www.sciencedaily.com/releases/2020/10/201026164426.htm>

- Successful treatment of dermatomyositis and associated calcinosis with adalimumab:
<https://www.semanticscholar.org/paper/Successful-treatment-of-dermatomyositis-and-with-Xie-Williams/ecc7aa353e7ac4d99c86dc5fe0339f8fa92bf267>
- Insights into myositis treatments – a good summary of all myositis types and potential treatments:
<https://journals.sagepub.com/doi/full/10.1177/1759720X19886494>
- A happy story from a dermatomyositis patient:
<https://my.clevelandclinic.org/patient-stories/310-woman-walks-again-after-painful-skin-condition-leaves-her-immobile>

Drug trial information:

- COVID injection for people without functioning immune systems:
<https://www.bbc.com/news/health-55022288>
- KZR-616 earns orphan drug status from FDA, for treating DM and PM:
<https://patientworthy.com/2020/11/02/experimental-drug-orphan-designation-polymyositis-dermatomyositis/>
- At-Home research study for patients with autoimmune conditions:
<https://www.clinicaltrials.gov/ct2/show/NCT01931644?recrs=a&cond=Myositis&cntry=US&draw=3&rank=11>
- A study of PF-06823859 in dermatomyositis patients:
<https://www.clinicaltrials.gov/ct2/show/NCT03181893?recrs=a&cond=Myositis&cntry=US&draw=3&rank=22>

Recipe Corner:

Some history about this recipe:

Hoppin' John is a dish popular in the Southeast US, likely originating in African culture. Tradition has that it is eaten on New Year's Day, often with a side of greens, e.g. collards, for good luck. The juice of the greens is sometimes beneficial if the beans get too dry.

Here is an account on the history of Hoppin' John, written by John Martin Taylor, himself a noted cook:

Throughout the South this humble dish of "peas" and rice is eaten on New Year's Day for good luck, with a plate of greens, cooked with a hog jowl and plenty of corn bread to sop up the pot likker. In Charleston and the surrounding Lowcountry, cowpeas — dried local field peas — are traditional. The classic Charleston recipe for hoppin' john is a very dry version of the dish, but it is served with greens in their juices — or with a side dish of more peas and pot likker.

"One pound of bacon, one pint of red peas, one pint of rice" — thus did Sarah Rutledge begin what may well be the first written receipt for this quintessential Lowcountry dish. As the daughter of Edward Rutledge, a signer of the Declaration of Independence, and niece of Arthur Middleton, another signer, Miss Rutledge was the "Lady of Charleston" who anonymously authored *The Carolina Housewife* in 1847.

Where the name originated is a matter of dispute. Still, the belief is that the dish arrived here with the slaves, who numbered in the tens of thousands in Charleston and on the neighboring rice plantations of the 17th and 18th centuries. Those West Africans were long familiar with rice cultivation and cookery, and the pigeon pea (*Cajanus*), favored throughout Africa, quickly took to the tropical environment of the Caribbean where so many of the hapless Africans were first shipped. *The Carolina Housewife* may have been written by a "Lady of Charleston," but dishes such as hoppin' john were staples in the "big house" that had been brought there by black cooks. Karen Hess, the noted culinary scholar, includes an entire chapter on hoppin' john in her treatise on the Carolina rice kitchen, but one needn't be a historian to understand that the slaves taught the master to love this simple dish.

Hoppin' John

(Courtesy of the Pioneer Woman, and Jim Bergeson, who hopes you enjoy this for New Year's as much as he and his family do)

Ingredients:

4 tbsp. butter
1 whole large onion, diced
4 cloves garlic, minced
1 whole green bell pepper, diced
2 stalks celery, diced
4 c. soaked black-eyed peas
5 c. low-sodium (or no-sodium) chicken broth
1 whole ham hock
Salt and pepper, to taste
Cayenne pepper or hot sauce, to taste
2 tbsp. white vinegar
White or brown rice, for serving

Directions:

1. Soak black-eyed peas in cool water for at least 6 hours. Rinse before using.
2. Heat butter in a large pot over medium-high heat. Add onion, garlic, green pepper, and celery and stir. Cook for 3 to 4 minutes. Stir in soaked beans, then add chicken broth, ham hock, salt & pepper, and cayenne to taste. Bring to a boil, then reduce heat and cover the pot for 30 minutes.
3. After 30 minutes, check the liquid level; if it's too soupy, cook with the lid off for another 15 minutes or so. If it's too thick, splash in a little more broth. Stir in vinegar, then taste for seasonings. Add more spice if needed.
4. Serve over white or brown rice, making sure to get plenty of the cooking liquid spooned over the top. Or, you may mix the bean mixture with the rice before serving.
5. Variations: Add red bell pepper, canned diced tomatoes, diced jalapenos, diced ham (instead of ham hocks), or sliced bacon (instead of ham hocks). Stir in torn-up kale when 5 minutes of cooking time remain. You can also use canned, drained black-eyed peas if preferred. Just use diced ham instead of ham hock and a little less broth, as peas won't need to cook as long. Garnish with chopped green onions if desired.

One-Liners To Make You Smile:

Whenever I try to eat healthy, a chocolate bar looks at me & snickers.

What do electricians talk about? Current events.

What happens when a duck flies upside down? He quacks up.

Did you just have twin girls? Name them Kate & Duplikate

What do you call an average ogre? Mediogre.

How do you kiss a florist? With tulips.

Why was the moon in a bad mood? It was just going through one of its phases.

What do you get from forgetful cows? Milk of amnesia

What's a room full of sauerkraut? Overkrauted.

What is the name of Obi Wan Kenobi's twin brother? Obi Two Kenobi.