



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

Volume 1, Issue 2

This is the second 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.

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

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**Upcoming Meeting Calendar**

All meetings are held from 1:00-3:00 pm at the DIRECT Center for Independence, 1001 N Alvernon Way, Tucson, AZ 85711

Friday, **May 8, 2020 (note date change from previous announcement)**

Friday, August 14, 2020

Friday, November 13, 2020

## Notes from February 14, 2020 Southern Arizona KIT Meeting:

The Arizona/Southwest TMA KIT group met on Friday, February 14, 2020, from 1-3 pm, at the Direct Center for Independence. Nineteen people were in the conference room, and none joined us via Zoom this time. Attending the meeting were 12 attendees who have some form of myositis and 7 attendees who were spouses/caregivers.

We went around the room, with new attendees discussing their myositis history, while prior attendees discussed what had changed for them since the previous meeting. This is a summary of status and potentially helpful ideas, with names withheld in the interest of privacy of the attendees. We celebrated Valentine's Day with some homemade treats (recipe at end of newsletter) and sharing smiles with quotes and jokes.

We discussed the importance of exercise, and played a Chair Yoga Dance with Sherry Zak Morris: <https://www.youtube.com/watch?v=7mwDjzXZ7Js> Sherry and the song, "I Can See Clearly Now" got us moving and grooving with simple movements while seated. There are many other short chair yoga dances, song selections, and other Yoga For Seniors videos available on YouTube with this instructor – they are a fun way to get a little exercise at home.

### Person 1 (JDM):

- Diagnosed in her early 20s and has had the disease all her adult life. She was fortunate to be able to have two children.
- She has been on cortisone all her adult life, and for a while tried IVIG but had very bad side effects (migraines). She now uses Hizentra, which is sub-Q immunoglobulins – she administers it to herself once a week. It has really been helping her skin.

### Person 2 (IBM):

- He is getting leg braces soon – there are two types: ones that cover the knees and lock your legs (bad kind for him) and AFO (Ankle and Foot Orthoses) which are below the knees and support your ankles. These braces are expensive, and are only covered by Medicare once every five years.
- His disease started in his ankles, and was diagnosed by the Mayo Clinic in Phoenix.

- He talked about a Honda exoskeleton device, which was given pre-market approval by the FDA:  
<https://hondainamerica.com/news/honda-walking-assist-device-receives-clearance-from-u-s-food-and-drug-administration/>.
- He mentioned some veterans may benefit from being declared catastrophically disabled by the VA. Here are criteria for that:  
<https://helpdesk.vetsfirst.org/index.php?pg=kb.page&id=2198>.
- He had a new seat assist lifting device that he places on his walker seat, which he bought from Amazon. He said it has been very useful for helping him get out of his seat. Here is a link:  
<https://amazon.com/Carex-Uplift-Premium-Assist-Memory/dp/B0056PQ684/ref>

#### Person 3 (Caregiver):

- His recent research has been on the role viruses can play in autoimmune diseases. In particular, his spouse was tested for Epstein-Barr Virus (EBV) and the test showed prior exposure to the disease (90% of people have been exposed to EBV in their life, frequently through mononucleosis). Her Western medicine doctor said the exposure was not active, therefore no treatment was necessary. Her naturopath suggested a 14 week virus treatment protocol. She is about half way through that, and has been feeling much better.
- This provides more reinforcement for the viewpoint of getting multiple opinions, and how important it is to find the right doctor.
- Here are a couple of articles that show a link between EBV and autoimmune diseases (not DM specifically):  
<https://www.the-rheumatologist.org/article/study-implicates-epstein-barr-virus-in-7-autoimmune-diseases/>  
<https://www.amymyersmd.com/2018/08/epstein-barr-virus-ebv-autoimmune-connection/>

#### Person 4 (DM, ILD, Raynaud's):

- She was diagnosed about 3 years ago.
- 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>.
- In the trial, there is a 40% chance of getting the full dose of Lenabasum, a 20% chance of getting a low dose of the drug, and a

40% chance of getting a placebo. At the end of a year Corbus Pharmaceuticals (the drug manufacturer) will do an Open Label Extension, where participants are invited to continue for another year with a guarantee of receiving the drug. This drug trial is still enrolling and there are two sites in Phoenix

- Since early November, she has been feeling much better – prior to that time she would get evening fevers for a few weeks every 30-45 days. Since early November she has had no fevers, improved lungs with less rattling, and increased energy. She doesn't know if it is the drug trial or the virus protocol (which she started on January 1, 2020), or a combination of both.

Person 5 (PM, DM):

- She was diagnosed in November 1994 with PM and DM. At that time not much was known about the disease. It took 5 years for her to be diagnosed, which was finally done through a muscle biopsy.
- Her initial symptoms were weak quads, falling and rashes. She had IVIG for a while along with methotrexate (these stopped working after a while), and she has been on prednisone for many years but is now down to 3 mg/day.
- Earlier in the disease cycle she had more PM symptoms, whereas now she has more DM symptoms.
- She has been feeling better since she has changed to a gluten-free diet, does chair yoga three times a week and walks more.

Person 6 (Caregiver):

- He said his spouse lost weight with steroids (three others also commented that this happened to them).

Person 7 (Caregiver):

- She maintains the Southern Arizona KIT Facebook page: <https://www.facebook.com/groups/2420947264622849/>. It's a private group, so you'll need to ask to join the group.
- She mentioned that there are many Facebook groups for different types of myositis, with a lot of useful information available through these sites.

### Person 8 (IBM):

- He has IBM, and was diagnosed in 2015 – it started in his hands.
- He accepts the fact that there is no treatment for IBM, but tries to exercise as much as possible to help maintain muscle strength.
- He has dysphasia (trouble swallowing), and gets frustrated when he can't do things he could do yesterday.
- He spent his career in the pharmaceutical world, and explained drug trials to the group. Phase 1 is a safety drug trial on a very small basis. Phase 2 is a little larger and will check for safety and efficacy. Phase 3 is a larger group (Lenabasum is planned to be 150 people worldwide) and is primarily checking for efficacy. He said most Phase 2 trials do not make it to Phase 3.
- He said Dr. Scherer at Banner (she is a neurologist) diagnosed his disease.

### Person 9 (NAM) and Person 10 (Caregiver):

- He has Statin Induced Necrotizing Autoimmune Myopathy (NAM)
- The onset of his disease was very sudden – he started falling in Oct 2019, and by Nov 2019 was in Northwest Hospital, then was transferred to Banner.
- He was started on prednisone, and seemed to respond to that but remained bedridden. He recently had his first IVIG treatment – it was initially denied by insurance, but with his wife's hard work (alerting doctor to lack of improvement) it got approved – he will have monthly IVIG treatments for six months, and has shown a positive response to his first treatment.
- Compass Health has been very good – they have sent PT and OT people to the house, along with caregivers to help his spouse, and they have provided a hospital bed plus shuttle transportation.
- The Banner Infusion Clinic on Ajo (next to the rheumatology department) has very nice, helpful staff.
- He was on Atorvastatin since 2011, and they doubled his dosage 3 years ago. He started having muscle tightening symptoms (not really cramps) but didn't want to go to the hospital. His spouse's message was to not downplay these symptoms, but to seek treatment early.
- She also commented that it has been very hard to get their family to understand just how sick he is.

#### Person 11 (PM/IBM):

- She was diagnosed in 2016 with PM, when she went to her 12<sup>th</sup> neurologist (Dr. Lujan). She then went to Dr. Holli Horak at Banner for a 2<sup>nd</sup> biopsy.
- Test results showed that she might have PM or IBM, but the doctor left the diagnosis as PM to provide more treatment options.
- She did IVIG for three years and had very bad side effects, including going to the hospital several times. She stopped treatments in April 2019.
- She also was diagnosed with Stage 1 lymph node cancer through a tumor that was found on her appendix when it was removed.
- She takes one day at a time and keeps a positive attitude.
- Her family and friends (other than those close to her) don't understand, because she doesn't look sick.
- She has trouble lifting her arms. She has learned to not be afraid to ask for help at the gas station and the grocery store, due to receiving kind assistance when asking.

#### Person 12 (DM):

- She was diagnosed with DM four years ago, but has a muscle biopsy coming up to confirm the diagnosis.
- Her main symptoms are brain fog, muscle weakness and itching.
- She sees Dr. Ortega at Barrow in Phoenix (a neurologist).
- She stays as active as she can – does yardwork & housework, yoga and walks as much as she can.

#### Person 13 (Caregiver):

- In support of our commitment to exercise helping those with myositis, his quote was “you rest, you rust”.
- He also added, “today is the youngest you'll ever be”.

#### Person 14 (IBM, LGMD):

- She was diagnosed with IBM in 2012 – it started in her quads.
- She was further diagnosed with Limb Girdle Muscular Dystrophy (LGMD) through a genetic test in 2016 – the symptoms are the same as IBM, but supposedly IBM is not inherited. She is skeptical about that based on her family history where her father had Muscular Dystrophy, and three siblings have/had autoimmune disease issues.
- She has no pain, but also no strength.
- She needs to eat slowly, has trouble swallowing, and has to drink liquids with food.

- She mentioned several tools that are important for everyday living – these include a toilet lift, a Hoyer lift and a scooter. She stressed that it is important to look at these devices if possible before you buy them, to make sure they will work for you (since they are all fairly expensive). She needs a new scooter, but has to wait until the end of her 5 year window so Medicare will help pay for it – her current three wheeled scooter is easy to tip over if you lean to one side.
- Note: After our meeting, Dr. Holli Horak (a neurologist with Banner) was contacted to clarify. She explained that both IBM and LGMD can have the same clinical presentation; and while at this time we manage both in similar ways, they remain two different diseases.

#### Person 15 (IBM):

- He is Person 14's brother, has IBM, and has been having some trouble breathing lately.

#### Person 16 (IBM):

- He was diagnosed with IBM in March 2017.
- He was in a car accident in 1972 and lost both legs below the knee plus part of his right hand and walks with prostheses and crutches.
- He continues to live an active life with his family including at one time mono snow skiing.
- His diagnosis was delayed as he had no legs to feel symptoms, but noticed that his hands were getting weaker.
- He lives in WA, and was fortunate to see Dr. Erik Ensrud in Spokane, who was familiar with myositis and was able to diagnose him quickly. Dr. Ensrud moved to Oregon, and he has continued to see this doctor there. Dr. Ensrud is moving to the University of Kansas soon, and this person will continue to follow the doctor around the country if necessary. He stressed the importance of finding a good doctor who understands your condition.
- He went to the TMA patient conference in San Diego in 2017, and found it very beneficial.
- He manages the disease through diet choices and exercise.
- He has trouble with swallowing, and he can tell he is getting weaker.
- An orthopedic doctor did experimental tendon transplants in his left hand, and it increased his wrist mobility.
- He researches everything he can, and says that information is power!

Person 17 (Caregiver):

- She had a career in Occupational Therapy, so she was able to help her spouse in many ways.
- As an example, she suggested a tool that enables him to pull his credit card out of a credit card reader. It is available at any hardware store: <https://www.acehardware.com/departments/tools/hand-tools/spring-clamps/22116>



- She said you shouldn't stay with a doctor who doesn't know what they are talking about re: myositis – even if you have to travel to find a good doctor – it's worth it.

Person 18 (IBM):

- Despite once being an Olympic-level competitive weightlifter, he was diagnosed 2 years ago with PM (and was unsuccessfully treated for it), but apparently has IBM.
- He came to this meeting primarily to get information on finding a good doctor – Dr. Scherer and Dr. Horak from Banner were both recommended.
- He was treated with methotrexate, IVIG and prednisone, none of which helped. His muscle biopsy was inconclusive.
- He is retired Army, and has insurance through Tricare.



Person 19 (Caregiver):

- Her spouse's doctor told him not to exercise, which is totally counter to all the experience many meeting attendees have had, and also counter to discussions with other doctors.

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/interest:

- Music can help your health:  
<https://newsinhealth.nih.gov/2018/01/sound-health>
- 10 minute chair follow along exercises:  
[https://www.silversneakers.com/blog/fyp-10-minute-chair-follow-along-workout/?utm\\_source=facebook&utm\\_medium=social&utm\\_campaign=edit\\_activity](https://www.silversneakers.com/blog/fyp-10-minute-chair-follow-along-workout/?utm_source=facebook&utm_medium=social&utm_campaign=edit_activity)
- Helpful hints on qualifying for disability with myositis:  
<https://understandingmyositis.org/how-to-qualify-for-social-security-disability-benefits-with-myositis/>

### Myositis/autoimmune articles:

- Novel treatment for DM digital ulcers:  
<https://pc.thejcn.com/DOIx.php?id=10.3988/jcn.2020.16.1.160>
- New insights into the treatment of myositis:  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6950531/>
- Interesting discussion on myositis antibodies:  
<https://rheumatology.medicinematters.com/myositis/diagnosis-and-screening/myositis-specific-antibodies-idiopathic-inflammatory-myopathies/17556384>
- Rogue cells at root of autoimmune diseases:  
<https://scienmag.com/research-pinpoints-rogue-cells-at-root-of-autoimmune-disease/>
- Selected highlights from the 3<sup>rd</sup> global conference of myositis, Berlin (March 2019). Note this also has links to summaries of some presentations:  
<https://bmcrheumatol.biomedcentral.com/articles/10.1186/s41927-019-0078-3#Sec1>

- Chinese medicine approach to DM (note: this doctor is trying to sell his services, which we are NOT endorsing – but he has some interesting ideas):  
[https://www.youtube.com/watch?feature=youtu.be&v=vAmQrqEL\\_EM&app=desktop](https://www.youtube.com/watch?feature=youtu.be&v=vAmQrqEL_EM&app=desktop)
- Not specifically myositis related, but interesting discovery related to autoimmune diseases:  
<https://theconversation.com/discovery-of-gene-associated-with-20-autoimmune-diseases-leads-to-promising-drug-trials-131957>

#### Drug trial information:

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

- Study of Zilucoplan in people with Immune-Mediated Necrotizing Myopathies:  
<https://clinicaltrials.gov/ct2/show/NCT04025632>
- Environmental risk factors for myositis in military personnel:  
<https://clinicaltrials.gov/ct2/show/NCT01734369?recrs=a&cond=Myositis&cntry=US&draw=2&rank=3>
- At home research study for patients with autoimmune conditions:  
<https://clinicaltrials.gov/ct2/show/NCT01931644?recrs=a&cond=Myositis&cntry=US&draw=2&rank=10>

#### 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 is:  
<https://www.goodrx.com/>

## Recipes and Jokes Corner

### Better For You Carrot Cake Cookies:

#### **INGREDIENTS –**

- 1/2 cup unsweetened creamy almond butter
- 2 large eggs (could replace with two flax eggs to make it vegan)
- 2 Tbsp maple syrup
- 1 tsp vanilla extract
- 1 cup finely ground almond flour
- 1/2 cup unsweetened shredded coconut
- 1/2 tsp baking soda
- 2 tsp ground cinnamon
- 1 tsp ground ginger
- 1/4 tsp sea salt
- 1/2 cup grated apple
- 1/2 cup grated carrot
- 1/2 cup raisins
- 1/2 cup raw walnuts chopped

#### **INSTRUCTIONS –**

1. Preheat the oven to 350 degrees F and line a large baking sheet with parchment paper.
2. In a mixing bowl, stir together the almond butter, eggs, maple syrup and vanilla extract until creamy.
3. In a separate mixing bowl, stir together the almond flour, shredded coconut, baking soda, ground cinnamon, ground ginger and sea salt.
4. Transfer the flour mixture to the mixing bowl with the wet mixture and stir well until combined. Stir in the remaining ingredients (apple, carrot, raisins, walnuts).
5. Drop cookie dough onto the parchment-lined baking sheet. Bake 15 minutes, or until cookies are golden-brown around the edges. For crispier cookies, bake 17 to 20 minutes.
6. Allow cookies to cool 5 minutes and serve.

Jokes:

Why didn't the skeleton send valentines? He didn't have the heart.

My doctor said I should avoid stress, so I've stopped opening his bills.

A man explained to a friend that his wife was upset he didn't buy her roses. "I didn't even know she sold them!" he exclaimed.

I'm at the place in life where running errands counts as going out.

Why don't they play poker in the jungle? Too many cheetahs.