THE MYOSITIS ASSOCIATION

KIT Connection

Helping support groups Keep In Touch

Southern Arizona Keep In Touch (KIT) Myositis Support Group

Volume 1, Issue 1

Welcome to the Roaring 20’s! This is the first edition of a more-or-less quarterly newsletter that is intended to provide notes from the previous quarter’s support group meeting and some information related to myositis, with an 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 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 one of these chronic illnesses – dermatomyositis, juvenile dermatomyositis, polymyositis or inclusion body myositis.

Vickie Jahaske & Rosemary Badian

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

Rosemary Badian
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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, February 14, 2020
Friday, May 15, 2020
Friday, August 14, 2020
Friday, November 13, 2020

Notes from 6 December 2019 Southern Arizona KIT Meeting:

The Arizona/Southwest TMA KIT group met on Friday, December 6, 2019 from 1-3 pm at the Direct Center for Independence. Twelve people were in the conference room, and one joined us via Zoom – there were four caregivers and eight people who have some form of myositis.

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 potentially helpful ideas, with names withheld in the interest of privacy of the attendees.

Person 1 (DM, ILD, Raynaud's):

- Initially diagnosed in early 2017
- Medication – myfortic (cellcept), sildenafil, cilostazol
- Tracking health progress and medications using a daily log or journal, since it's hard to remember what happened when.
- Food is medicine, and diet choices make a huge difference. Going gluten free, cow dairy free and reducing sugar have helped this person. Food sensitivity testing, while expensive, helps people understand their body – we are all different. After considerable research, two helpful food sensitivity tests are available through: https://cellsciencesystems.com/patients/alcat-test/ or

  https://nowleap.com/the-patented-mediator-release-test-mrt/

- Daily gentle exercise helps increase flexibility and reduce joint pain. Qigong and other stretching routines twice daily have made a huge difference – but it takes 12-18 months to start to notice a difference.

Person 2 (Caregiver):

- Research has been very helpful to learn tips to improve one's quality of life
- A book by Sarah Ballantine, "The Paleo Approach: Reverse Autoimmune Disease and Heal Your Body" is a very good reference book, and while this individual doesn't agree with all it suggests, it is useful to look up information on different autoimmune disease topics.
- Research has shown that there are three things necessary to get an autoimmune disease: genes, an environmental trigger and leaky gut. Personal observation shows that many Western Medicine doctors

don't understand that there may be smoldering infections which don't incapacitate us, but make life harder for people with an autoimmune disease. Functional Medicine doctors or naturopaths understand this much better.

Person 3 (DM, ILD)

- Initially diagnosed in 2014 by a neurologist at Phoenix VA (Dr. Sivakumar).
- Manages the disease with azathioprine, eats whole foods, and goes to the gym most days.
- Cognitive Behavioral Therapy (CBT) has helped mentally cope with the disease, and meditation is very helpful.

Person 4 (PM, DM)

- Initially diagnosed 25 years ago, but took 5 years to get diagnosed.
- Became ill most likely from working in a building with environmental issues, mom had rheumatoid arthritis so had the genes for an autoimmune disease.
- Going to a therapist and doing CBT have been very helpful.
- Team of doctors work very closely together – that is key to successful health care with this disease.

Person 5 (IBM)

- Initially diagnosed in 2014, was declining for 10 years prior to diagnosis.
- Takes no medications, thankful that disease has had slow progression. Main trouble is with legs.
- The most important message is "don't give up". Walk as much as you can and go to the gym every day. A therapist has helped with anxiety and coping skills, and this therapist is also available to spouse.
- Wants to try things independently, gets very frustrated when that isn’t possible.

Person 6 (Caregiver)

- Therapist has helped deal with interpersonal friction created by disease.

Person 7 (PM)

- Diagnosed in 2014, was very active before that.
- Did IVIG for 3 years, stopped because of expense when switching insurance.

- Finds meditation to be helpful, and maintains a positive attitude towards life.
- Eats all foods as part of this outlook on life.
- Recommended a 1991 movie that is available on Netflix: "Triumph of the Heart" - it is about a football player who has DM.

Person 7 (IBM)

- Diagnosed with IBM in 2015 after several misdiagnosis attempts.
- Went to a neurologist at the Mayo Clinic in Phoenix and got a correct diagnosis.
- Finds the conference tapes from TMA to be very helpful.
- Has recliner on 4x4s to help make it higher, main trouble is with legs.

Person 8 (IBM)

- Diagnosed in 2015, had symptoms since 2009.
- Main trouble is with hands, pain varies by day and time.
- No special diet, goes to personal trainer who specializes in helping those with special needs and elder care twice a week with spouse.

Person 9 (Caregiver)

- Personal trainer has helped show how to pick spouse up after a fall if needed.
- Work out on power plate – very helpful.
- Having a hobby has been very important for spouse’s mental health and wellbeing.

Person 10 (IBM)

- Had disease for 18 years, wasn’t diagnosed until 2017.
- Has other overlapping autoimmune conditions (celiac, osteoporosis)
- Deals with anger and has gone to therapists to get help.
- Socialization is always a challenge because one never knows how one will feel, so can't plan.
- Learning to simplify and to try to "let go", to help deal with these difficult emotions.
- CBD oil helps with pain.

Person 11 (Caregiver)

- Trying to get power chair to allow spouse more freedom.
- Planning for wheelchair van to go with power chair
- Staying in house and remodeling to make it wheelchair accessible.

Person 12 (IBM)

- Just moved to independent living facility in Phoenix – good to move while you're still mobile to a facility that provides increasing levels of care.
- Talked about a dermo-skeleton technology device developed by a Canadian company. (https://www.b-temia.com/.) They only sell their devices in Canada and Europe right now, but they are currently doing trials in Boston and Chicago.
- Discussed a natural food allergy tincture that is custom made, which has helped. It is from the Family Allergy Clinic in Phoenix.

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:

1. The Institute for Functional Medicine, “Rise of Autoimmune Disease Linked to Intestinal Permeability” (some information related to how important our gut is to our health)

   https://www.ifm.org/news-insights/ai-rise-autoimmune-disease-linked-intestinal-permeability/

2. Noteworthy – The Journal Blog, “The United States has an Epidemic of Processed Food — and it’s Killing Us” (a long article, but some interesting facts on processed food and what it does to our bodies)

   https://blog.usejournal.com/the-united-states-has-an-epidemic-of-processed-food-and-its-killing-us-bb3a9a9a0547

3. Podcast: Health, Nutrition and Functional Medicine – Dr. Ruscio Radio - drruscio.com (several interesting podcast topics related to autoimmune diseases in general)

Myositis specific articles:

1. National center for Biotechnology Information, National Institute of Health, “Dermatomyositis: An Acute Flare and Current Treatments” (good general overview of Dermatomyositis) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6582284/

2. National center for Biotechnology Information, National Institute of Health, “Inclusion Body Myositis: Update on Pathogenesis and Treatment” (good general overview of Inclusion Body Myositis) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6277289/

Treatment and drug related information:

1. Gabapentin FDA warning:
   https://www.fda.gov/drugs/drug-safety-and-availability/fda-warns-about-serious-breathing-problems-seizure-and-nerve-pain-medicines-gabapentin-neurontin

2. Inclusion Body Myositis Arimoclomol drug trial:
   https://cureibm.org/arimoclomol-receives-fda-fast-track-designation-for-inclusion-body-myositis/

Drug trial information:

www.clinicaltrials/gov (this is a useful site – search on Myositis, Arizona)

1. Dermatomyositis Lenabasum drug trial:
   https://clinicaltrials.gov/ct2/show/NCT03813160?term=myositis%2C+arizona&draw=3&rank=17
   The Honor Health Phoenix site isn't actively recruiting, but the Mayo Clinic site in Phoenix is.

2. Abatacept Inflammatory Myopathy study:
   https://clinicaltrials.gov/ct2/show/NCT02971683?term=myositis%2C+arizona&draw=2&rank=5
   The Neuromuscular Research Center in Phoenix is recruiting

Helpful Resources (with a focus on Southern Arizona):

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 lower cost medications and durable equipment is:
https://www.needymeds.org/

Used or discounted medical equipment might be available through the Arizona equipment loan closet, Numotion.
Begin with this form:
https://secure2.convio.net/mda/site/SSurvey?ACTION_REQUIRED=URI_ACTION_USER_REQUESTS&SURVEY_ID=45776
More assistance is available from the Arizona MDA office:
Marilyn Hardy, Care and Clinical Services Specialist
Muscular Dystrophy Association
7975 N. Hayden Road, #C-370, Scottsdale, AZ 85258
Phone: 480.496.4530

Southern Arizona Myositis KIT Facebook page:
https://www.facebook.com/groups/2420947264622849/. It can also be found by searching for Southern Arizona Myositis Support in the Facebook search box. It's a private group, so you'll need to ask to join the group.

A local gym that specializes in helping seniors and those with special health needs:
Prestige Fitness
4490 N. 1st Ave
Tucson, AZ 85719
Ask for manager: Tara Ashbaugh – 520-465-3324, tell her you were referred through the Myositis newsletter

Two Tucson doctors who are very familiar with dermatomyositis:

Dr Holli Horak, Neurologist, 520-694-8888
Dr Carolyn Bangert, Dermatologist, 520-694-2873
Both are part of the Banner medical network.