

**COLORADO MYOSITIS SUPPORT GROUP  
MAY 2, 2015 MEETING RECAP**

The May 2, 2015 meeting of the Colorado Myositis Support (KIT) Group was held at the Swedish Medical Center in Englewood, CO, from 10:00 AM to a little after 12:00 Noon. There were 14 people attending comprising of 10 myositis patients and 4 spouses.

Group leader, Mo Bolger, opened the meeting by welcoming everyone and announced that our scheduled speaker for the meeting, Wayne Connell, founder and president of the Invisible Disabilities Association (IDA), could not be there due to illness. We hope to have Wayne speak to us at the August meeting of the Group. Mo also noted that an attempt to replace Wayne's talk by sharing a presentation from the last TMA Annual Patients Conference was stymied by problems getting his laptop to communicate with the computer projector in the room. Mo announced that our next regular Group meeting will be on Saturday, August 1, 2015, from 10:00 AM to 12:00 Noon, at the Swedish Medical Center. The room number will be provided in an email announcement sent out to the Group before the meeting.

We were delighted to have six new members attending the meeting. They are Janis Mullinnix from the Fort Collins area; Larry Sharp from Colorado Springs; Ian Stewart and his wife, Linda, from Buena Vista and Iris Trumbull and her husband, Robert, from Estes Park. We welcomed these new members and expressed our appreciation to them for travelling such long distances to attend the meeting. Another new member, Cirel Egelman from Colorado Springs, was also planning on attending, but couldn't because of a last-minute conflict.

In lieu of a speaker presentation, the Group had a wonderful round-robin discussion in which the people attending the meeting introduced themselves and commented on how they were doing. This was a great opportunity to get to know the new members and have them get to know the "old" members. A brief summary of our discussions is given in the following paragraphs.

Mo Bolger was diagnosed with DM eight years ago. Mo and his wife, Nicole, and their son, Conor, live in Highlands Ranch. Mo said he experienced a severe flare of his DM last summer, which caused him to go on disability for several months and required several trial attempts to get his medications and his DM in balance. He has returned to work, but his DM is still not controlled as well as before.

Ian Stewart was diagnosed with sIBM in January 2015. Ian and his wife, Linda, live in Buena Vista. After his diagnosis, Ian said he did some online research and discovered a paper by Helene Alexandersen, a therapist in Sweden, describing an exercise program she developed for IBM patients. This exercise routine has been found to show improvement in as little as 16 weeks. Ian gave this paper to his PT in Buena Vista and she used it to work out a special exercise program for him that requires only about 20 minutes each day. Since doing these exercises, he has noticed a definite improvement in his balance and coordination. Ian noted that Helene Alexandersen will be giving a presentation at the next TMA Annual Patients Conference in Orlando. Ian and his wife, Linda, are planning on attending that conference. Ian also said he will talk to his PT, Dr. Tammy White, about giving a presentation on this exercise program to our Group.

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Corrine Nylander was diagnosed with sIBM in 1997 and lives in Denver with her husband, Fred. Corrine noted that at the time of her diagnosis, she was told not to exercise because it was thought that it would harm the weakened muscles. Now, almost all medical people knowledgeable about IBM strongly recommend that patients follow an appropriate exercise program. However, it should be an exercise program that is designed for people with IBM. Corrine also pointed out that there is an excellent medical supply store in Denver called YouCan TooCan, which sells assistive devices for people with disabilities including: kitchen, mobility, bedroom, bathroom, eating and drinking aids. (*YouCan TooCan is located in the Plaza De Monaco Shopping Center, 6460 E Yale Ave, Denver, CO 80222, 303-759-9525. Their website, <http://www.youcantoocan.com/> is currently being updated and is not yet up and running*).

Iris Trumbull was diagnosed with DM in October 2014 after a skin biopsy. She and her husband, Robert, live in Estes Park where Iris remains active in outdoor activities and gardening. However, Iris noted that she must wear protection, not only against the Sun, but also from indoor fluorescent lighting.

Janis Mullinnix was diagnosed with sIBM about one year ago. Janis is from the Fort Collins area and like all of us who have been diagnosed with this disease has had difficulty coming to terms with it. She said she has a lot to learn about IBM. All of us hope that our support group can help her as much as possible in this quest.

Claud Deen Tochen, who lives in Parker, said she was diagnosed with sIBM in 2003. She said her IBM is progressing slowly and she is able to get around fairly well with the help of a cane. She also noted that she does light exercises, which she finds helpful.

Jerry Davis was diagnosed with sIBM in 2005. Jerry lives SW of Denver in an unincorporated area of Jefferson County near Littleton. Jerry said he really appreciates the Colorado Myositis Support Group and the support it provides to those with Myositis.

Larry Sharp lives in Colorado Springs and was diagnosed with sIBM in June 2014. Larry said he remains very active in working around the house and gardening. He has established a future plan and time frame for accessibility modifications to his house based on the progression of his IBM. It was agreed that planning ahead is something all of us with IBM should be doing.

John Mozer lives in Aurora with his wife and caregiver, Sheila. John said he was initially misdiagnosed with PM in 1990 and then re-diagnosed with sIBM in 2006. John's neurologist believes he has had IBM since 1990, but that its progression has been very slow. However, his arm and leg muscles have gradually deteriorated over the past 25 years to the point that he now needs a walker to get around the house and a power wheelchair on trips outside of the house.

Art Ford and his wife, Diane, live in Lakewood. Art said that in 2005 he was also misdiagnosed with PM and then correctly diagnosed with sIBM in 2010. After his PM

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misdiagnosis, Art was put on prednisone, which has caused significant osteoarthritis to develop in his body along with his IBM. Over these past years, Art has experienced a lot of falls and he strongly recommends that those with IBM plan ahead due to the progression of the disease. Art mentioned that there are websites, in addition to the TMA website ([www.myositis.org](http://www.myositis.org)), that provide helpful information on IBM and how to cope with it. Examples are sites by: Mike Shirk (<http://lifedisabled.com>), Bill Tillier (<http://www.ibmmyositis.com>), and Dagmar Slaven (<http://www.myomusings.com>).

NOTE: Unfortunately for us, Art and Diane will be moving to Omaha, Nebraska later this year, where they are building a new home with built-in accessibility features such as lift and transfer rails in the ceilings, ramps and a fully handicapped accessible bathroom. We wish them all the best and want them to know that we will miss them greatly.