

Northern California Fall Meeting Summary

Our KIT meeting at Eden Medical Center on November 1 was a great success!! Thanks to everyone who could attend, and for those unable to attend we hope to see you in the Spring!

We gained new members at the meeting including those with all 3 forms of myositis and their care partners, swelling our attendance to a new record of 30! Jackie and Judy both brought baked treats, and Halloween candy was donated as well by Kim.

The morning session was dedicated to discussing the Annual Meeting of TMA that took place in Reno last September, and encouraging those who can to attend next year's Annual Meeting in Orlando, FL. I shared the information that can be found on TMA's website about the Annual Meeting, including the list of many of the presentations, their powerpoint slides when available and some of the actual videos of the presentations that are included. Many of the presentations and videos from previous conferences are also available on the site. Members of our KIT that attended the Reno conference were invited to share something they learned or experienced from going there in person.

Everyone who went attested to the unparalleled experience of meeting so many afflicted with the same rare disease that you have!

Marlene Wesson (IBM) enjoyed encountering the researchers and hearing updated information about the ongoing drug trials for IBM such as Follistatin and BYM338.

Alvin Buhignan (IBM) enjoyed discovering how others with his disease cope with ADLs such as rising from a chair, thereby finding his own method to be unique!

Traci Taylor (PM) discovered our KIT group exists!

Several members attended Dr. Levine's session on dysphagia and learned why troublesome mucus in the throat is likely due to myositis.

Our own KIT member, MaryAnne Hunt-Valencia (IBM) gave a talk on using her Myositis Service dog for assistance in many aspects of daily living. She also mentioned how useful the Muscular Dystrophy Association has been to her and to others in our group. They can be reached locally at the Forbes-Norris Clinic, 2324 Sacramento St, San Francisco, 94115; 415-600-3604. Rich Stevenson (IBM) praised the MDA's ability to speed up much of the red tape involved in getting durable equipment items such as scooters.

Carla Stevenson, care partner of Rich Stevenson, talked how she enjoys seeing friends at these conferences that she only sees once a year. She and Marti Wright greatly enjoyed the sessions and panels for caregivers.

I have PM, and in Dr. Pestronk's session I learned that some experts want to discontinue the use of the words PM and DM and refer instead to Immune Myopathies. His studies on muscle biopsies show distinct differences in cell clumping and staining that could be helpful in refining and re-defining categories of muscle disease, including DM, PM and perhaps even IBM. This ultimately might help with better targeted treatments and more accurate prognosis.

The after lunch breakout groups were lively and helpful for everyone. As always, it's great to share your own experiences and hear those of others with similar conditions!

We hope to see everyone again in the Spring, the date to be announced (hopefully) soon. Generally we try to get a speaker, and have already gotten some suggestions about physical therapists who are knowledgeable about myositis.

As usual, feel free to contact me with ideas, comments, suggestions or questions!