

Summary Of ECD Global Alliance Internet Chat

18 Jun 2016

9 Attendees

- A member, whose husband has ECD and has been on Vemurafenib (V), told us last week that he had gone on a shopping trip. She had thought that he was walking around the store with the grocery cart, but it turned out that he was "zipping along" with a scooter - "like a maniac" - according to his brother, who met him there.
- A member has just started Pegasys injections (a form of interferon). She said that she felt great and her eyes were less swollen. She had had an "upset tummy" and a little headache, but they were "tolerable". She has been told that she will be seen at Mayo in 4 weeks, but doesn't have the appointment yet. She has a local doctor, but she hadn't seen him for herself since she was diagnosed. But she took her daughter to see him last month, so he knows what is going on.
- A member who is considered in remission is taking 2 Vs a day and doing well. He is planning to go back to Mayo soon, to see Dr. Garrity and Dr. Habermann.
- Our new Australian member is not taking any drug treatment yet. He said that he was "feeling much better since I got a new mattress this week!"
- An American member is going away for a month with her sisters. They are going to galivant around, and then joining up with her husband and lots of family. She will "pretend" that she is well for the month.
- Drs. Go and Habermann were both commented on as being very good. One member said that she wished that she had seen Dr. Go when she was at Mayo 2 summers ago. She did not get any diagnosis, just noted to be complaining of leg pain, dizziness and weird bumps on her skin. They did not do a simple leg X-ray or a brain MRI scan.

She is still on 3V a day and has emailed Dr. Diamond to ask about going down to 2V a day. He wants another MRI before she does that. She is suing the insurance company because they would not let her have a PET scan that had been requested. At the moment, she has 5 joints that are troublesome, dizziness, shaking of the right hand, and a possible colon infection. She has twice sent in a "sample" to look for C-diff after she had been on Augmentin for a chest infection. But the sample was not dealt with correctly so she is just taking probiotics and drinking Keifer. She is a bit better.

She gets a rash due to the V. The bumps on her skin are ECD skin lesions that have histiocytes in them. She was originally given a diagnosis of Multicentric Reticulocytosis. The skin lesions were biopsied. But until Dr. Estrada-Veras, at the National Institutes of Health (NIH), got hold of them from Lexington and Mayo, they weren't fully studied for the V600E, S100, etc.
- Another member has colitis, but it is in remission. He said that he was curious about her "colon infection". When they did a PET for him last December, they thought that he had a full-blown flare-up of colitis. He didn't feel that it was. He had a colonoscopy, and it wasn't a colitis flare up. He is under the impression that it is very unusual to have ECD in the colon.

- Another member said that she has a rash on her stomach, but her primary doctor says that it is just dry skin. She has found that every time she asks whether something could be ECD related, or due to the V, the doctors always have a different opinion.
- The French member who has been waiting for biopsy results has had ECD confirmed. His dermatologist has told him that he will ask his colleagues to offer treatment. He has had some small skin lesions which lasted for a couple of days. His initial diagnosis was made from a bone scan of his femur. He told us that he has no brain lesions.
- Members discussed the merits of various fiber products that help keep the bowels regular. Psyllium husk is supposed to help reduce cholesterol and the chance of colon cancer. Chia seeds and flaxseed (which needs to be ground up) were mentioned.
- Someone asked whether there is a difference between the joint pains that people get before V and those that they get afterwards. A member who started V fairly recently has had a sore shoulder since February when he had an MRI. This pain has gotten worse. His physiotherapy team are going to look into whether it is due to a problem in the tendons.
- V is supposed to cause joint pain, and some of the participants on the V trial dropped out because they couldn't tolerate the joint pain.