

Summary of ECD Global Alliance Internet Chat

8 April 2017

7 Attendees

- A member has just got home from a trip to New York City to see Dr. Diamond. Her scans all show stability, but the joint issues are still bad. This is probably from the dabrafenib (D). Physiotherapy is not helping. It appears that D is no better than vemurafenib (V) for her joints. She has been seeing a shoulder orthopedic specialist for many months, and will be seeing him again in May. She has a cyst in her shoulder, but he is very reluctant to touch her...so she lives with the pain. She took her shoulder and cervical spine scans to NYC, and Dr. D is going to have the radiologist there officially read them. She is waiting to hear from him.

Dr. Diamond suggested going off the D for a month or decreasing the dose some more. Her wrist is red and a bit swollen, and her left shoulder is always painful. She wants Dr. D to decide whether to do this or not. A member who swapped from V to D has had no side effects at all. A member said that, based on some old readings, D was supposed to have more side effects than V. She said that Dr. D had told her that D is no better than V for joints. He thought maybe COBI (a MEK inhibitor) would be a switch that would have no joint side effects. But her scans are stable, so maybe a change in drug might not be a good idea. She is still dizzy. Dr. D didn't say whether results, so far, from the COBI trial, are showing it to be effective. But this was the first time he had even offered it as a treatment. In December, he told her that she lived too far away to be in the trial, but this time he didn't even mention the trial. She isn't planning to go back to see Dr. D until the ECD conference in October.

She did say that she has more energy now than before, and has a veggie smoothie every day and drinks wheat grass. She saw her eye doctor a couple of weeks ago because her eyes are so dry on D. She uses eye-drops. The doctor also suggested using a warm eye mask every morning because there is so little oil in her eyes.

- A member is going back to Mayo to see his optometrist and hematologist this week. He will be having a very thorough check of his eyes, and talking about maintenance options. He is now in remission having had V treatment.
- A member's wife came on and said that they were finishing off a snack at a coffee place. Then they are going grocery shopping near his new apartment which he moved to this week. It is in a supported complex. "The place is great." He feels at home, and is getting along well with both his new flat mates and the support workers.

They still need to figure out the transportation issues for getting to appointments. They think that using public transportation could take 3 to 4 hours, compared with just a half-hour drive.

- A new chatter came on and her message was in Spanish. Google Translate came up with the following translation: "Good afternoon, greetings I was treated from January 2015 to January 2016 Interferon, but I have not yet recovered."
- One member said that she understood a little Spanish, having learned it as a child in Texas. Her accent is good "but that's all".

- A member, who has been more unsteady and feeling unwell, is having an MRI of her head and spine this week. All her bloodwork is fine, and she has a checkup scheduled for the end of May. She sent an email to the doctor this week to say things were not going well. He suggested she get an MRI soon. Her primary doctor put in a request for the MRI in a hurry, and the scan is due next week!

She has had three falls in three weeks, and her stiffness is worse. She is now dependent on her sticks. Her balance is bad, too. She thinks that the stiff legs make it much worse. She is on one V a day now, having had V treatment and been in remission for some time. The dose was reduced to one V in October. She is "Hoping my ECD is not waking up again".