

Summary of ECD Global Alliance Internet Chat

01 July 2017

8 Attendees

- A member said that he had had a severe pain in his right leg for a few days and trouble walking.
- The member who has recently discovered that she is pregnant came on the chat. She feels "completely exhausted and walking poorly, other than that Ok." Her partner has had a week's vacation so they stayed at her parents. She will not be visiting again until after the baby is born. Her parents live a two hour drive away from her. She is now 24 weeks pregnant. She is sure that it will not last the full 40 weeks!
- The member who has recently had shoulder surgery said that no tissue had been taken for biopsy, because there hadn't been any that looked suitable. She feels that the surgeon was a bit "miffed" to have even been asked! Her joints/tendons/bones are her biggest problems. Although she has lesions in her brain, that doesn't bother her apart from being a bit off balance. She has recently seen the shoulder surgeon. The shoulder still hurts and she is continuing with physiotherapy. She has a PET scan coming up. She has not been on chemo since April. She told the doctor that her leg was hurting, but she didn't tell him that she had a few "heart issues, swallowing issues, etc." She is not sure whether she will go back on chemo, and is waiting for the PET scan. She is sure that Dr. Diamond wants her back on dabrafenib (D), or something else. It was her decision not to go back on D after May 10, and although she has no regrets, she doesn't think that the ECD is in remission. She will be at the beach in North Carolina the third week of July, and she doesn't want to be on a chemo that keeps her out of the sun!!!!
- A member who is in remission after vemurafenib (V) treatment said that he would not dare to think that he could be off anything! But he thinks that what she is doing is "a good experiment" and whatever she finds out is going to benefit others. He said that he hopes that patients can take something milder than V and D for maintenance.

Urine testing for BRAF status was mentioned. She wondered whether her level had changed, and this is linked with relapse. A member came on after the Chat and said that the urine sample test for BRAF mutation is great. His doctor had used this instead of a biopsy. He said that it almost always correlates with biopsy results, and that his doctor got him the test "for free!"