

Summary of ECD Global Alliance Internet Chat

30 April 2016

6 Attendees

- On this Chat there was a new member from France. This made things a bit confusing. One of our Canadian members knew how to use Google Translate and so we got by. This summary is all in English!
- A member came on to leave us a message that he has just changed medications, from vemurafenib (V) to dabrafenib (D). This was because his liver enzymes became very raised on the V. Everything seems to be going well. There have been no side effects, with the exception of little bumps on the sides of his arms and on his thighs. He has just been to the dermatologist for a routine check-up and things were fine.
- Dabrafenib is about 30% cheaper than V for a similar dose. D is not approved for general use yet (neither is V!). This will mean that D is going to be difficult to get hold of by our Canadian members. One of these was too tired to come chatting (although his wife did come on). He has been on V for 6 weeks now. He had had a busy week with lots of appointments.
- A new member from France came on that has had ECD for a few years. He is treated in Paris at the "Pitié Salpêtrière" hospital and sees Dr. Julien Haroche. He is BRAF+ and is on V (dosage of 1 in the morning and 1 in the evening). He was on 2+2 before but he had "many skin problems" at this dose. He finds that he is still "always tired". He has been jobless since 2012.
- An English member also had this tiredness problem and he is now taking growth hormone, and is feeling much better.
- A US member told us about his work experience. He is an independent consultant, but couldn't work much in 2014. Once he was on V, he was able to get back to work late in 2015, and in the last few months he has completed 2-3 projects. The workload is unpredictable as a consultant, without having all the "fun and games" of ECD to contend with.
- The member, who was represented by his wife, feels pretty good and the V (2+2) is "doing something for him". He will have to wait for another few months for another PET scan. In Canada you can only have a limited number of PET scans (every 3-4 months?).
His wife's family has recently been to see him and they were very impressed by what V has done. He was very animated, moving his hands and doing his party trick... (moving his hands up in the air). He even shocked his brother by drinking wine. (Although it was non-alcoholic. No booze when you are on V!!).
- The new French member said that he had "signed up" with an insurance company so that he would have some income if he were jobless. He said that he has 4 children (boys aged 6, 9, 13 and 16) and "a pretty wife!" In France you pay tax, and when you're ill you don't pay for the medicines or the hospital. If he did have to pay for his medicine, it would cost more than he receives each month.
- A US member is still paying the bills from the clinical trial treatment that he had during 2014-

2015. And he has been adding on more bills since then; from maintenance visits, scans, blood work, etc.

- In Canada you don't have to pay for the hospital but you do have to pay for the medicine that is prescribed.
- Another new US member came on. He is from Florida and was diagnosed as having ECD, after 5 months and many tests to determine what was the reason of the pain in his tibiae. (An ex-doctor writes: That is the proper plural of tibia. Not many people know that!) He is not on any treatment yet – he is travelling to Orlando for a first assessment and a plan for treatment. He is not capable of working and finds that having too much time on his hands is not helping him mentally.
- Members spoke about Mike Livings in FL. He has recently passed away. Articles have been written about him. (<http://www.tcpalm.com/news/education/indian-river-county-schools/mike-livings-son-of-vero-beach-coaching-legend-dies-3155482f-56b8-5b0d-e053-0100007fe71b-377038901.html>) He was an important person in the sports community and did a lot to raise awareness of ECD while fighting it for over 10 years.
- After the Chat had finished a member logged on who had been at a wedding party. She had recently been to see Dr. Diamond. He decreased the dose of V that she takes to (2+1) because she has so many side effect issues with her joints.