

Summary of ECD Global Alliance Internet Chat

29 Aug 2015

7 Attendees

- A member told us that she was doing well, apart from having sustained a hairline fracture in her left leg. This happened in a car accident about 3 weeks ago, which happened when she was leaving a parking lot. She is pleased that she should only have about a week left in the boot! Another member said that his wife had to wear a boot for weeks. She had fractures from running. The member who has the fractures lives in Indiana and is BRAF negative. She goes to the University of Chicago, and Comer Children's Hospital (she is one of our youngest members!) and was most recently on Kineret. The doctors believe that she may be in remission.
- The member who has done so well on vemurafenib (V) said that he is starting to get some small bumps on his shoulders. His doctors don't want to lower his dose of V because the bumps are not bothersome. They are so small that you only notice them if you look closely. The dermatologist prescribed something for him (he isn't taking it because "They wanted \$60 for it...").
- A member who is on sorafenib (a cousin of V) said that she always get bumps, but they are tolerable, even though they aren't that small. She has been prescribed an antibiotic ointment to put on them.
- A member on V since February has bumps on his shoulders, chest, legs, and abdomen. The doctor gave him some cream, Bacitracin, to put on the bumps. The doctor said that the bumps were skin infections, and that the cream would clear them up. So far it has worked very well. He has been doing pretty well on V, but during the last couple of months he has had a lot of pain and swelling in his hands.
- Liver blood tests were discussed. One asked whether anyone had has a raised alanine aminotransferase (ALT). For another, the only thing really elevated is alkaline phosphatase, although it went down significantly after he had been on a dose of V, 4 in the morning and 4 in the evening. His medication was not adjusted.
- Another member told us that she had started on 4+4 of V, took only 5 doses and reacted. She restarted after 2 days on 2+2. Her brain MRI on Aug. 3 was not improved, so she suggested that she go up to 2+3. She did and she sees her oncologist this week. She is going to ask to go up to 3+3, because she wants to see the lesions go down.
- Another member has just invited one of her neighbours (this is the UK way of spelling it!) over for dessert tonight. She is a neuro-ophthalmologist and the member, with macular edema, wondered whether the neuro-ophthalmologist might have some thoughts on what could be causing this. The retina specialist that she sees, knows nothing about ECD, has no idea why edema is there, and has no idea how to treat it. Avastin shots have not helped. She is on sorafenib (a treatment for ARAF+ patients) and will be having an MRI of brain and orbits, and PET, soon to see if the sorafenib has worked. She said that she might ask to go back on Kineret. She has been on high doses of steroids for the eyes and she has gained over 20 lbs.

- The son of a member has a job in the Hamptons until the end of October. Then, he flies out to New Zealand for 5 months to work a golf course! He is only 22, and gets paid!
- A member has just had 5 days of Medrol (steroid) for her inflamed shoulder, but it's still inflamed, so physiotherapy is the next step. She was supposed to have a PET last month but her insurance said no....hopefully they will think again. Blue Cross/Blue Shield (BC/BS), her insurer, has never paid for a PET because the only one she has had was at the NIH. She didn't qualify for the phase 2 trial at NIH because her brain lesions were 2 mm too small, so she is under the care of a private oncologist now.
- Members mentioned how noisy MRIs were (although the machines in the UK have got a lot quieter).
- Others who are on V told us about the effects on appetite and weight. One had gained a few pounds, but doesn't know whether it is the V. One lost 25 pounds and the V changed the taste of all food and drink. She has lost her taste for coffee, and now drinks English breakfast tea in the morning! Another has lost about 10 pounds this summer because she is "just not hungry".
- Members discussed the article that Memorial Sloan Kettering had in the New England JM last week. The average response to V is about 6 months. A member asked whether this meant that if you have shown improvement in six months, then you just go off the drug. A member, who has responded well to V, said that his doctor had said that "everyone he's treated on the drug has shown some improvement".
- The website www.rareconnect.org was spoken about. A member who uses it said that it is another way to connect with other ECD patients, and can share your experiences in depth. Some had an account, but others did not.
- Vemurafenib and fertility was the next topic. No-one knew the effects that it might have. Apparently no one has tried to have children on the drug (!), even though it has been used for melanoma for years. One member has frozen sperm just in case, but wanted to try naturally. They have been told that his wife could possibly get side effects from the drug. It was said that someone should talk to a doctor that has used it for cancer for many years, or maybe we should look on the web. The package insert does mention the possibility of side-effects, but fertility is not even mentioned in the literature of V.