

Summary of ECD Global Alliance Internet Chat

14 Jan 2017

7 Attendees

- A member having cycles of chemo is in cycle 7, and day 8 or 9 is when she starts "feeling pretty sick". Her pain comes directly from her bone lesions. Nausea is caused by the medicines. For another member, joint issues come from the chemo, and bone issues from ECD.
- A member had just been to see the film "Fences" and said that it was a "gorgeous" film. It is set in Pittsburgh post World War II. Denzel Washington directs and stars in the film.
This member is starting the third week of dabrafenib (D). She had previously been on vemurafenib (V), but this was not "doing the job" and she had side-effects. She began a slow increase of D on January 1. She soon begins to take 100mg in the morning and 100mg in the evening. She has what she calls a "chemo" cough and dry skin from the D, but no fevers. When she was on V she had lost some hair on her head. This grew back, but stayed short. Vemurafenib didn't seem to work well on her brain lesions, but it did make the lesions in her body "go to sleep". She had so much trouble with her shoulders, hands, and feet that she was switched to D.
- Another member who also swapped to D is going to carry on at 150mg in the morning and again in the evening, until the end of the month when he sees Dr. Diamond to have a scan. His skin is dry, but a little lotion is enough to treat it. He had lost hair while on V and nothing has grown back. Most of his hair loss was from his arms and legs. He had had his three month dermatologist appointment on the previous day. He had a tiny cyst removed, which has been sent to the pathologist. The dermatologist said that she doesn't gamble, but she would put money on it that it is just a cyst.
- A new chatter asked whether many of us had managed to continue working. One said that she had to quit work (physical therapy nurse/chaplain) because her local oncologist told her not to drive. She was too tired to work anyway, and dizzy too. Another chatter said that he was working still (in Kindergarten).
- The new member also asked whether anyone else was on the COBI trial like her. Nobody on the Chat was on COBI and no one knew of anybody else on it.
- "Foodstuffs" were discussed. One member said that she had decided that if she was going to take "poison" twice a day to try to treat the ECD, she might as well also take stuff that should be good for her. An organic juice bar has just opened near where she lives, so she is taking a "shot" each day of wheat grass. Also, a neighbor is bringing her a green smoothie every morning. The neighbor makes a blender full for her husband and kids. She also cooks bone broth from bones at the butcher's shop. A broth of bone made from the calf's foot was recommended. Old writings suggest that the jelly from this could be good for the joints.
- We were told that organic fruit and vegetable juices are good for health if you add Omega 3. A member went on to a 100% plant-based diet when she found out about the tumors in her bones.
- Members mentioned what they liked to eat. One said that she has cut back on dairy and gluten products, although she had just made a "wicked" potato, bacon, and cheese soup.

- A chatter said that every time she thinks that it will be OK to go out, it is too snowy or too icy. She is just starting the process of packing for an upcoming week away to Toronto. In part, they are doing this to celebrate their 25th anniversary. There will be a lot of doctor appointments, but some quality time and dinners too, hopefully. They have been approved for one year of coverage for V in Canada. All that is left to do is the paperwork!! This will save them thousands of dollars. The private insurance will have to pay for the V. In turn, it will save thousands of dollars that her father would have to pay in premium for the year and coverage will go back to normal.
- The need for EKGs and echocardiograms(Echo) was discussed. EKG shows the heart rhythm, and Echo shows the heart function. One of the members who has swapped from V to D had had to have an Echo for the V trial, but not when he swapped to D. Another has just had an Echo ordered by her local oncologist. She is now on D, but when she was on V she had a great many EKGs to make sure that her Q-T interval was less than 500.
- The member on the COBI trial gets an Echo ever other month.
- A member in remission after their V treatment has slipped on icy straits and fractured some bone in her spine. It seems to be healing, but is still painful, although not as bad. Luckily she was holding on to a handrail when she fell.

Her case was presented at a dermatological conference a few years ago, which is how she finally came to be diagnosed as having ECD. She started having symptoms when she was 11 or 12, and finally started having many different issues at 14. She has it mainly in her bones, some skin lesions, and in her brain. She is BRAF negative and is currently not on any treatments. She had interferon and then anakinra. She graduated from school last year, and she is trying to run her own petsitting business. She has tried a few jobs and the pain is too much. When she is moving she is not in so much pain, so she really enjoys walking. A counselor advised her to start her own dog walking business since she already takes care of animals for family members.
- Another member is having her case presented, too. It is to be presented by a dermatologist that she saw several years ago, at which time she was given a wrong diagnosis! The meeting is January 27-31 at the Winter Skin Seminar in Park City, Utah. The doctor wanted to know if there were any skin lesion photos from her original visits. At the beginning, Mayo Clinic had taken tons of photos, "like I was in an Olan Mills shoot".
- It was mentioned that Dr. Diamond had said to a member that he has a patient who has come off D and gone on to once a week methotrexate, [summarizer's comment: weekly methotrexate is my treatment, and has been for some years].