

Summary of ECD Global Alliance Internet Chat

13 Feb 2016

8 Attendees

- A member who is on vemurafenib (V), has had his dose increased from 2 in the morning and 2 in the evening to 3+3. His dose had been reduced earlier, but the doctors think that they reduced the dose too fast. He is doing well now. He had had some problems with swelling while on the lower dose. He was also having some problems with his voice-recognition software1.
"Everything doesn't play out exactly the way I said!"
- The daughter of a Canadian member has written an article about him and would be happy for it to be shared with others. It is at <https://medium.com/@KendraPG/what-s-wrong-with-how-canada-supports-rare-diseases-it-doesn-t-1ccec6c367a#.qa5u40nsb> .
The subject of this article has a "big doctor appointment" coming up this week. The hospital and insurance are still talking about the funding for the visit. They think that the V prescription may become available this week.
She asked whether people find they get more sleepy than usual, and also whether anyone was having a problem moving their feet when they wanted to.
In reply to this, a member said that he was always tired, but he has found that exercise really helps him to fight his fatigue. His treatment with V has helped him to regain a lot of energy, so it's definitely better than being without V. Another member on V agreed with this, and another said that he was always tired, and that his sleep was "all messed up". He gets up, eats breakfast, sits down to watch a bit of TV, and falls asleep! In the afternoon he gets sleepy again.
- A member on 2+2 since December, thinks that her body is getting tired of the chemo after 10 months. Her fingernails are peeling (although not actually coming off), and her feet are getting calluses even though she is treating them. She has blisters on her lips, and her hip and knee joints are hurting.
It was said that if fingernails are peeling off then she may have a bad case of hand & foot syndrome from V. She sees her local oncologist this week and will show her the blisters, her feet, and nails. She has also developed "cysts" under the palms of her hands (2 on each palm).
- A member suggested a website that may help people to think of all the other factors that may be causing the peeling of the nails at <https://www.caring.com/questions/tiny-strips-of-skin-just-below-my-fingers-nails-start-to>. Regarding problems with fingernails, it said that sometimes peeling nails are the result of too much moisture that then dries them out. You can protect your nails by applying a clear nail polish. One with nylon fibers may be especially helpful in strengthening the nail. Also iron deficiency can affect the nails so eat foods containing iron (such as baked potato with skin, fortified breakfast cereals, lean meats, lentils, spinach, and white beans)
- The member with the nail problem had recently spent a couple of days at the Grove Park Inn in Asheville, NC. She had used the indoor pool, which is saltwater. A member wondered whether

the saltwater could be the reason for the nail problem, and suggested that she tell Dr. Diamond about all this.

- In answer to the second part of the query, a member said his feet move all right, but he had lesions in the soles of his feet which make it hard to walk, and also in the palm of his hands. He is unable to make a fist. His knees also make “popping” sounds. He told his doctor, and she started him on physiotherapy three times a week to see if this would help. It has helped some, but not completely. He thinks that you “just have to keep walking and working your hands”. Rubbing his hands brings a little relief.
- A member told us that she hates vacuuming and she has just bought a Roomba, a vacuum that goes around doing the cleaning on its own. [Summarizer's comment. I've got one of those, she's called Jo!] So, the member has got her feet up while the Roomba does the work! Their 65lb labradoodle is scared of the Roomba so she finds another room to be in during cleanings.
- Another member has a dog that barks at the vacuum cleaner. She wondered whether it would bark at the Roomba. Actually the schnoodle barks at everything, including when the member with ECD is choking or coughing too much. She even barks at him when it is time to go to the table and eat!
- One member has to eat carefully because he has ulcerative colitis as well as ECD. This flared up in recent months. To stay healthy, he eats and sleeps well, and always tries to find ways to move his body, hands, and legs. He tries not to sit too much, and takes daily exercise.
At diagnosis, he had lesions in the eye orbits, brain, spine, sinus, and in all long bones. One mass was so large it was blocking blood flow to his brain. This was the main concern of the doctors. Vemurafenib “pretty much takes care of them all!”
- The member who will probably be starting V soon has a mass in the cerebellum. He will find out more this week when he discovers what a test shows. They are planning a “bone test” this week (probably a bone marrow biopsy). The doctors still need to get an answer to his problem with excessive platelets.
- A member asked whether anyone had trouble with muscle loss. She is having trouble with her right leg. Her treatment is working for her rheumatoid arthritis (RA) and ECD (report from both doctors) and they do not want to change. Her PET shows great improvement everywhere else.
- One member said that she swims and has physiotherapy twice a week to help strengthen the hips, knees, and shoulders. She is trying to get her “core” in better condition to help her balance. She flexes her muscles every day, but each PET scan shows increased metabolic activity within the bilateral calf musculature. Her CRP (C Reactive Protein a sign of inflammation measured from blood work) is always high. She is BRAF+, but is on Kineret instead of V. It was suggested that she might try V for a brief period instead, and see what happens.
- One member learned that an increase in activity/uptake on PET may be due to inflammations that have nothing to do with ECD.
This member saw serious uptake in his digestive tract on a PET. Obviously, the immediate conclusion is that the ECD has spread. But upon further analysis, the doctors determined that

this was not likely. He had colonoscopy and other tests to confirm that. The colitis was treated separately.