

Summary of ECD Global Alliance Internet Chat **21 Nov 2015**

7 Attendees

- Members were looking forward to Thanksgiving. It will be a special time to be with family and friends.
- A member asked whether anyone else has a problem with dry skin on their feet and large calluses building up. The build up of large calluses is due to Vemurafenib (V), and is common. There are many ways to control and remove them, and they need to be actively removed. For his dry skin, one member often uses skin lotion, or grapeseed oil, after having a shower. The oil is a problem over time as all the clothes, bed sheets, etc. have turned yellow after oil got onto them.
- A member came on who has just had ECD confirmed. This was his first Chat, although his wife has been on a few times and told us his story as he moved towards a diagnosis of ECD. He had final confirmation this week that he has ECD and is BRAF+. This was a relief, of sorts, as he has had 8 years of hearing them say "You have something wrong but blamed if I know!" They are thankful that they now have a diagnosis and can start the search for treatment. Since he is BRAF+ he was encouraged to think that V will take care of a lot of his issues.
- A member who has had V treatment told us of his experiences. When he was on a high dose of vemurafenib (4+4, 3+3) he had a lot of issues with skin, hands, and feet. His liver could also be affected, and this was often indicated by dark/tea colored urine. He knew that going on a high dose for a long time was not a good thing. He started working hard to alleviate the side effects. He is now on 2 pills a day, and is planning on going down to only 1 soon. He said that he was "feeling great", taking daily exercise and has almost no side effects.
- The question of insurance approval for V was raised. The newly diagnosed member is Canadian, living in Ontario, not far from Toronto. It was said that currently, some of the patients in the US are getting coverage by their insurances after appeals. This is because there are now a lot more supporting published data than even a year ago. However, the insurances have their hands tied if it's not FDA approved.
- Another member was asked about his story. He was started on Interferon in November 2005, and continued on this until February 2015, at which time he started V. He feels very fortunate that he was in the military, as he gets his medical care through the VA. He has just an eight dollar co-pay. He said that he is "so glad I was in the Army".

While on the interferon he was exhausted all the time, had no energy, and had balance issues. Since 2005, he has had bone pain in his long bones, which moved from place to place. On V he still has balance issues. At the moment he has very dry skin on the bottoms and sides of his feet. He has developed large calluses on the soles of his feet. His hands are also affected. He cannot close them all the way, and has difficulty opening jars and soda bottles. The calluses range from the size of a nickel through to a quarter. He sees a podiatrist at the VA, and has been given some cream and lotion to help control the dry skin. They take care of the calluses for him.

He has a shower chair in the bath tub, and sits there to take a shower. He uses some olive oil and mild soap while in the shower. He has woodworking as a hobby but, because his hands "still do not work right" he has had to put his Christmas project on hold.

- It was said that salicylic acid based creams/lotions are good for the soles of the feet because it's very hard to get to that area. One member uses a tool for removing dead skin that his wife bought for him. It's working pretty well for both his hands and feet.
- After the new member had his ECD diagnosis confirmed this week, his wife has been researching the treatment options, one of which was V. She asked about the cost of the medicine, is this covered by insurance, and is it possible to get V through a trial (and if so what percentage of the cost is covered).
Vemurafenib is available in Canada, but the price would be anywhere from \$8,000 to \$12,000 CAD a month, depending on the dosage! The other drugs that are available are dabrafenib (D) - 2 twice a day 75 mg= \$8829 CAD, and trametinib (T) - 2mg, once a day= \$10,106 CAD.
Drug therapy would be recommended by Dr. Estrada-Veras, who has been involved in getting the diagnosis. The issue now is now the paperwork involved in getting the insurance and/or the provincial drug program to pay.
- A member said that he thought that D & T together are in the clinical trial at the National Institutes of Health (NIH). V is standalone treatment. He asked whether they had spoken to Dr. Estrada-Veras about getting into the D & T trial, although he said that he doesn't think that they should bother with pursuing this option, unless it's absolutely free. It is now so much easier to get V because of all the available data about it. They intend to explore all options in Canada first.
- A member came on who works with dogs (she actually had one with her at the time of the Chat!). Her ECD is "in remission", and she isn't taking any ECD medication at all now. She takes gabapentin, for pain, and Cymbalta. This is an anti-depressant drug, and her main problem now is depression. Her family is not helping at all, and usually makes things much worse. They do not understand her depression and don't care to learn. She said that she tries her best, but her family "just throws everything" at her, and if anything is wrong she always get the blame. She can control her depression in all other situations.
A member said that when things like this come at him he tells himself that "Life is too short, and I am too old to let all this get me down". The problem with family can be that people with ECD do NOT look sick, and they forget that we are.
- It was said that having someone to talk to about the problems would be a help. In Canada, CBC (the national broadcaster) has a show that goes around the country to talk about mental health.
- For one member, his parents and siblings are all Canadians, so he is very interested in finding out more about drug coverage there. Of course, people only worry about it when they need the medicines.
- A member had noticed that some members had had to appeal to insurance for drugs. In the US, your lead ECD doctors are supposed to help put the evidence for the appeal together. That is why this is not something that a regular practitioner can help with. One member received approval for V with the help of his doctors at Mayo, but he decided to go to Memorial Sloan Kettering for the trial.