

## **Summary of ECD Global Alliance Internet Chat** **19 Sep 2015**

6 Attendees

- A message had been left by another member to say that he could not be on the Chat today.
- A member told us that she was doing well apart from having a little back pain. She thinks that maybe she "slept wrong"!!
- The conference being only a few weeks away was mentioned.
- A member who has had treatment with vemurafenib (V) said that she felt that she had accomplished a lot over the last year. She has been "working out" hard, and it seems to have paid off! She was asked by another member (a female who is taking V too), whether she had lost her hair while on the treatment. The member asking told us that her hair had thinned so much that she is reconsidering how it should be styled. The member being asked about her hair said that hers had got quite thin, but she didn't lose it all. After one year it started to grow back, and it was curly! Now she has "Lots and Lots of Curls"  
She had a check up this week, and everything is OK. She has also talked to another ECD patient in Norway, and she told him about the Alliance.
- A member has recently had a steroid shot into her shoulder, but it is still painful. She has had a deal of trouble staying asleep at night because of pain. She said that the "only thing that has seemed to help is a bit of lavender oil on my finger and toenail at night". She has had issues with joint pain for years, so she doesn't know what has increased this pain. Members wondered whether it could be due to the V.
- Shoulder problems had affected another member. She said that she had had many shots into her shoulder, but unfortunately none worked for her. She eventually had surgery to clean out the excess bone, and this helped.
- Hard foot skin was mentioned. A member said that salicylic acid cream helps the dead skin to peel off. There are also tools to just grind it off, and "they work just as good". [Summarizer's comment: It all sounds a bit scary to me!]
- A member has talked to a patient from the V trial at Memorial Sloan Kettering (MSK). She was on the LOVE trial (a trial which allows her to get off the V, but to get back on it anytime). She had a flare-up after 2 months off the V, and is now back on V again.
- A member who is on V wondered whether the brain lesions (white matter in the cerebellum and pons) leave "shells" when the histiocytes are killed by the chemotherapies. The reason that she asks is that her PET from a couple of weeks ago shows much improvement in her legs and lung, but the MRI on her brain was only "stable". Two other members said that their MRIs of the brain are also "stable". The point was made that you have to differentiate PET vs MRI. You can have a "lesion" on MRI that will not show up on PET, if it is inactive. Sometimes, the tumor will disappear on both MRI and PET and that "would be ideal".

- The member who started this topic wants to drive again. Her cautious oncologist told her not to drive on May 1st, and she hasn't since. But she has never had a seizure or blacked out. She does get dizzy walking, but when driving she can hold onto the steering wheel! Two other members told us that they had no problems with driving, although one did admit that she gets dizzy often, and many times walks as if she is drunk.
- A member, who has been using Kineret (she is BRAF-), told us that now she is not taking anything, as her doctors think that she may be in remission. She thinks she stopped all the medication about 4 months ago. Her hematologist is the primary doctor taking care of her ECD, and he took the decision to stop medication. Her imaging was staying stable, her pains had greatly decreased, and her lesions were also decreasing. The doctors wanted to see how she did without medication. She is treated at the University of Chicago and she gets lab work every 3 months. It used to be every month. Scans are based on her symptoms, but will be at the least every year.
- Eye symptoms were discussed. Some members felt that they were more common in the BRAF - patients. It seems that a lot of ECD patients have eye problems, regardless of BRAF status. One of the Chatters is BRAF +, and he has a lot of issues. A fairly new member also had eye issues until he went on the V study at MSK. He is BRAF +.
- One member was going to have dinner that night with their neighbors. The woman is a neuro-ophthalmologist, and the member is going to ask her about eye issues with ECD. She has been told that her eyes are fine (and the scans show that too), but about once a month she gets something like an "aura". For about 15 minutes she looks out and "it seems like there are waves of water".  
She has been on V for about 4 months now, and it has helped with both her leg and lung problems. But she is still dizzy, and the brain lesions are only stable.  
She thinks that skin lesions are lessening, but not going away. But the V has given her many more skin issues so that it is hard to tell what is what. She had had skin lesions for some years before, always being told that they were "multicentric reticulohistiocytosis". Just when she had learned to say and spell it, a doctor at Duke University discovered that her newly revealed brain lesions, and long bone lesions (on x-ray) gave reason to biopsy the skin lesions again. This biopsy came from a lesion on her leg. NIH and Dr. Estrada-Veras uncovered the BRAF + mutation, and ECD was diagnosed.
- The member who recently had her shoulder injected, told us that the radiologist had done his fellowship at UCSD and knew of ECD.
- A new member, whose husband has been tested for suspected ECD, said that she had just got news, on the day before the Chat (through the urine test) that her husband is slightly BRAF +. She is wondering about "the next step". She knows that a PET and biopsy will need to be done but she doesn't know where. Her husband has a brain stem lesion (causing ataxia), markings on his legs, and probably hairy kidneys (this hasn't been confirmed yet). She has some resources to provide to the family doctor, and at the moment, the family is just living with the relief of getting some information. They also wonder whether there may now be a possible route to go through - instead of getting nowhere.  
He isn't on any medication for ECD yet. He just takes the usual medications that he takes for a heart problem. She has noticed that he does react to some medicines. He seems too sleepy and some of them seem to make his decline worse. He has needed to cut one of his tablets in half, as he had a "dramatic decline". Recently his balance has become worse.

They live in Canada, which has a much smaller population than the US, and they are more spread out. So there is not as much knowledge of ECD in the country. She has just found out that there are only 4 hospitals with PET machines in Ontario. She knows where 3 of them are, so it is a matter of telling the doctors to move in this direction. She asked whether V helps to make all the problems go away. A member who has been having V said that it depends on how advanced the ECD is. "V doesn't take care of everything."