

Summary of ECD Global Alliance Internet Chat

26 Sep 2015

5 Attendees

- One member has been having some good results when her retina has been tested for macular edema over the last 3 weeks. But she told us that it had come back. Her vision is not good, and she has had to increase her dose of steroids.
- It was asked whether anyone had any news about any new ECD medications, but nobody had any.
- A member, who is now off treatment, told us that he finished chemo last December. He is staying stable, with no growth or shrinkage of lesions. He had had a kidney transplant prior to the diagnosis of ECD, so he is on drugs to prevent rejection. He was on cladribine (a chemotherapy drug) for 6 months (injections for 5 days in a row and then a month's gap). He didn't find this treatment too difficult to take. He said that he sees his hematologist every 3 months and has scans every 6 months.
- Another member had been on cladribine in 2012, but this was changed to clofarabine before she had had a full 6 months of treatment. After 2 months of the cladribine, her scan showed no improvement, so her doctor then switched to Clofarabine. This had a very bad effect on her immune system and her CD4 count (a type of cell in the immune system) has yet to recover.
- A member who is now on vemurafenib (V), said that he can hardly use his hands, because of swelling and pain, and he is having trouble with balance as well.
When he started V he had an increase in energy. He had been on interferon for 10 years, then switched to V, because he heard so many others say how great they felt with V. He has been on a dose of 4 pills in the morning and 4 in the evening since February 2015. It was said that was still quite a high dose, and it was suggested that it might be helpful to stop the V for 1-2 weeks so that his body can recover. And then resume the V. He is going to consider this, and maybe consult with his doctor about this idea.
- Another member said that balance is his biggest problem. He thinks that it probably is caused by the lesion in his head. "Just tying my shoes is a chore." [Summarizer's note; all my shoes are slip-ons, and I've got a long shoehorn so I don't have to bend down so far.]
- A member on a low dose of V (just 2 a day) said that on his last PET, it appeared that his ECD was coming back in his spine, and that this might have been due to the low dose. However, his doctor thought that this could be an indication that the lesion is healing. These 2 options could look similar on a PET. He will stay on 2 pills of V for now, but he would like to stop it altogether, if possible.
He also had a blood mutation test which showed that he is negative in 30+ types of mutations, including BRAF.
- A member living in Canada said that V is not approved there yet, and he is not really sure whether he wants to try it, because of the possible side-effects. His doctors are also unsure partly because he takes medicines to keep his transplanted kidney working. He wants to discuss all of this with some of the doctors at the conference. He is BRAF +.

He was recommended not to turn away from V because of the possible side-effects. A member who has had V said that the benefits outweigh these (side effects), if you manage the dose and side effects carefully; like in a clinical trial.

- Another patient who lives in Canada has tested BRAF + on a urine test and is waiting to find out whether his doctors have enough info to take a biopsy.
His eyesight is not affected, and his cerebellum area is not thought to be responsible for his balance problems. He will be having another MRI on Oct. 8th to look at the area. He has also had his neck fused, so he has "a lot of health issues to deal with...".