Summary Of ECD Global Alliance Internet Chat on 29 June 2013

8 Attendees

- Our new Brazilian members came on at first, but couldn’t stay.
- A member told us that he will be traveling from the US to Europe (Switzerland), next month, to attend the wedding of his sister’s daughter. His sister married a Swiss man. And then, after the Swiss wedding, he travels to Maine for his son's wedding.
- Recent medical developments were mentioned, specifically the work surrounding the BRAF mutation. This mutation has also been found in some patients with advanced malignant melanoma. A drug (vemurafenib) has been developed to try to help melanoma patients with this mutation. A number of ECD patients have been to found this same mutation. The drug is VERY expensive. The drug company, that makes it, has a trial open, which allows for ECD patients to be part of the study. ECD patients with the BRAF mutation are eligible to be considered for the trial. Patients enrolled in the trial must be treated at a center involved in the trial, and return for check-ups about every 3 weeks. A recent publication indicates that a few ECD patients with the BRAF mutation had good results with this treatment.
- Members discussed their ongoing treatments for ECD. One has been on “low dose” methotrexate (40milligrams) once a week, for a few years and this seems to be holding things. The doctors have said that this treatment will be continued “until it stops working”!
- Another member has been taking Kineret daily (generic name anakrina) for about 2 years. Before that interferon was used for about 9 years. Changing from interferon to Kineret has massively reduced the side-effects that were experienced. The member told us that he had not appreciated how much the interferon had debilitated him until it was stopped. But the interferon had kept the ECD in check, and even reduced the fibrosis behind his eyes. He told us that he had “no complaints”.
- A member has recently seen the ophthalmologist, and it was found that the field of vision, vision in general, and optic nerve have all improved. The ophthalmologist is going to do a sonogram in 6 months, to get a closer look at the nerve. Normally, the optic nerve is not able to repair itself, and so the doctor was very surprised at this. The member was asked to encourage the doctor to write a case study to publish in one of the medical journals.
- A member has just had her first visit with Dr. Janku. The member has more tests scheduled and then will revisit Dr. Janku. Kineret was mentioned as a possible

treatment. But first, she is going to have more studies on the head and heart. It is hard to get all the appointments in because her husbands is, himself, on chemotherapy.

- A member told us that they had been to NIH, and found out that there was no ECD on her organs, but the skin, lymph nodes, and bones are affected. The member's chemotherapy is over at the end of July, and she is a little scared. Next week she goes for more radiation treatment.

  This is aimed under the right armpit, and at the left leg, where there are nodules by the knee and hip. This will be her 5th treatment course, and they last 2 weeks. She feels that she has done well with radiation treatment, but ECD is all "so scary" that she wants to just ignore it, and pretend it isn't real. She has been able go back to work for 4 hrs a day, 2 days a week. She was congratulated on this. Her doctor does not think that she is ready to stop chemotherapy, but the member wonders how she will know where she stands, if she stays on it. She asked whether any of the other ECD patients felt that they were getting better. One answered he was just the same as before, although he has managed to lose some of the weight that he gained when he was on steroids.

- A member came on who had ECD, and then developed acute myeloid leukaemia too! He had a bone marrow transplant 5 months ago, and is doing well. The cancer is gone, and he is waiting to hear about the ECD.

  He is being treated in Pittsburgh at the Hillman center. A paper is being written about his case. They wonder whether the cancer was brought on by ECD, or by being on Interferon for so long. He is still having treatment, and is not allowed to be more than an hour away from the hospital. He was congratulated on the outcome of his transplant. We (the Global Alliance, that is) will be VERY interested to read the paper, and to see what happens with the ECD after the transplant.

- A member said that he was going to San Diego on Nov. 1-2 for the patient gathering. Another chatter said she was also planning to be there, and she hopes that many people will be able to attend.