

Summary of ECD Global Alliance Internet Chat

21 Jan 2017

- The Chat had only a couple of attendees. They said hello, asked where everyone was, and logged off!
- In the week before, a member had posted a long message so I will summarise this:

He started by saying that he was something of a "veteran" of the ECD world and that he would like to share some of his experiences. He has often been through the same experiences that those more newly diagnosed are having to cope with. A couple of weeks ago a member said that she didn't know if the chemo was worse than the disease. "She hit the nail on the head!" He said that he had nearly every symptom that was listed as a possibility with vemurafenib (V). Most have subsided, but not so much with the skin lesions. He goes to the clinic monthly where it is "slice and dice time", with lots of skin biopsies. He did end up with a basal cell carcinoma right in the middle of his nose. A plastic surgeon removed it and performed a skin graft. Now it is not noticeable. He asked whether we feel that going to the doctors becomes our "social life".

He sees Dr. Scheel and "his amazing PA, Nancy". [Presumably this is the "amazing" Nurse Nancy Feeley!] There are still things such as joint pain, unsteadiness in walking, and various other ailments that come and go. Even so, because he has involvement everywhere except in his brain, it has been "arduous". He is on Anakinra injections and a dose of one pill in the morning and one in the evening of V. He is stable in the things that are related to ECD.