

Summary of ECD Global Alliance Internet Chat

24 Dec 2016

6 Attendees

- A UK member had left a message to say that due to the time differences, he would be tucked up in bed waiting for Santa at the Chat time. He hopes that Santa can make it all the way to the US after all those mince pies and all that sherry.
- A member told us that she was in Lake Geneva, Wisconsin (she must have meant BY the Lake, and not IN it, surely) for Christmas in two feet of snow! She is having a family Christmas.
She is going to swap from Vemurafenib (V) to Dabrafenib (D) in January, and her insurance, BCBS, will pay! She has had continuing problems with joint pains. Another Chatter said that he had never been troubled with joint pains while on V.
- A member came on to give us the fantastic message that he had had a follow up PET scan at Mayo that week, and had been told that the results were "remarkable". The doctors were very surprised that he had had such a great response to V. Even though he was diagnosed only 4 months ago, he is now "on maintenance" and his next visit is not for six months.
- A member said that he had been on V from when it was first introduced. His PET scans, last MRI, and ultrasound show that all progression has stopped for now. He has found that side effects from V come and then go. He says, "You have to balance them with being able to survive ECD!!"