

Summary of ECD Global Alliance Internet Chat **June 23, 2018**

8 Attendees

- A member started the Chat off by explaining why he was using a new name. Member was told that his regular name was in use. The member stated that he had been on Interferon for a long time, but it had stopped working. Now he is on vemurafenib and has seen some improvement. Like others he is having the usual difficulties with the sun. He sees Dr. Palmeri. He also stated that he will likely not make the conference in Orlando.
- A member stated that she had to wear a mask to protect her nose and lips because the effects from the sun were so bad. She was on vemurafenib for 18 months, now she is on Mekinist.
- A member said that he had just returned from a four-day vacation in Shipshewana, Indiana, and had a great time.
- Our French member is still having pain in his legs. His Kineret has been doubled for one month.
- Several members compared their vemurafenib doses. The member, who stopped vemurafenib while pregnant and then restarted, is doing OK and is just taking one dose in the morning and one in the evening. The member who switched from Interferon to vemurafenib is taking eight a day. A high dose, but all his pain is gone. Another member is doing great with the one vemurafenib daily. However, he is having some tingling in his face, which he thinks could be a side effect. Although he is on a low dose, he feels that some rare side effects could still kick in when taken long-term.