

Summary of ECD Global Alliance Internet Chat **October 20, 2018**

7 Attendees

- A Norwegian member said that she was doing well on just two vemurafenib (V) a day. She manages to exercise daily. "A day without exercise is not a good day." She said that exercise is her second medicine and without it she gets very stiff. Her daughter is now one year old.
- A French member saw Prof. Haroche two weeks ago. He is still having pain in his legs and hands. He has been using Kineret for the last two years without much result, apart from stability of his disease.
- A US member, in remission, had been on one V daily for over two years with no major issues until recently. Now, he is on one every other day, and will likely stay on that dose until he can find another option. He thinks there are only a few patients that have been on V for as long as he and the Norwegian member have. He also believes in the benefit of exercise. In particular, it helps him deal with the side-effects. When on one V daily, he would take a nap and run a mile every day. That was when he was in San Diego, where there was an exercise room in the apartment complex.
- The conference to be held in Italy was mentioned. It will be July 11 and 12, 2019. The French member may go if he can get train travel. There was a discussion whether patients would be speaking about their experiences. The Norwegian member said that she would love to share her story again. A US member said that he thought that the Norwegian member's experience is unique, and many people would like to hear and learn from it. She would have liked to go to Orlando this year, but it is a little too far for her daughter.
- The US member told us of his pleasure with meeting two other members when he was in New York last month.
- The French member has been in the hospital in Strasbourg and he distributed the poems that he had been writing. He also told us that Dr. Haroche has written a short report on ECD, which he has on his personal computer and can share to make the disease better known. It is a video document and will soon be available on a rare disease platform, but will be in French.
- Another US member came on. She had been to Trader Joe's to buy ingredients to make black bean and sweet potatoes enchiladas that night. She said that the US wind was "crazy." When she eats tonight, the French member will have already gone to bed!
- She reminded us that she had a cardiac catheter test recently. Her coronary arteries are clear enough. The cardiologist thinks that this makes her ECG and BP bad. She manages to exercise six days a week, but lifting weights gives her pain in her chest.

She said that they have had frost on their pumpkins, but no snow, and asked other members to put photos on Facebook "if they could, when they have snow."