

## **Summary of ECD Global Alliance Chat**

### **17 June 2017**

8 Attendees

- One member told us that she spent hours organizing all of her medical things, "so much fun!" She had also found an article that was just published that week at Genetics Home Reference on Erdheim-Chester. It is short and organized, link to article: <https://ghr.nlm.nih.gov/condition/erdheim-chester-disease>
- Our member, who is a teacher, said that school is not out yet. He has a week and a half to go. He likes to go to horse race meetings, but there weren't any that day. A member said that she lives only three miles from the race course in Lexington. She invited him to come and visit with his wife.
- Some members are planning to arrange doctor visits to coincide with this year's ECD conference. One member wonders whether Dr. Diamond will not be pleased that she has changed from a private clinic, near where she lives, to University of Kentucky (research at their cancer center). She doesn't want to lose contact with him. She will be seeing him again soon, and is having a brain MRI this week, with attentiveness to the pituitary. Then, someone will "decide about chemo." She has not been on any since April 11, and is "loving it."

She is rehabilitating her shoulder at the moment, after surgery. A member said that it would freak him out to not be on any medication. A UK member is only taking a once weekly dose of methotrexate. He has been in remission for some years.

- A member gave us all a pleasant surprise by telling us that she is pregnant! She hadn't thought that this would be possible. She is now five months pregnant, and did not realize until she was three months, so the baby has had some Zelboraf in the early stages. The scans show that she is expecting a girl. [Editor's note: CONGRATULATIONS!!!!]
- The member who had told us that he was going to a multi-faith meeting said that he prepared "an excellent dessert" with the fruits of the Bible, (i.e., figs, dates, grapes). He has also been harvesting a good crop of cherries for two days. His wife has made preserves and jam. In the next week, he is going into the hospital for treatment to control his intestines.

On a lighter note, he told us that he had agreed to count the swallows in his village. These birds make their nests on the houses, and their song is very nice. At the moment, they are "feeding their little ones."

- The availability of trials at the University of Kentucky (UK) was discussed, since one of the members is moving her care there. The only ones that she had been told about were NOT at UK. One was at Dana Farber in Boston, one was with Dr. Diamond, and one was at Vanderbilt. Nashville is only 3 1/2 hours' drive from her; and her son and daughter-in-law live there.

There is also the complicating factor that she has been on two kinase inhibitors, so that may preclude her participation in any trial. It was said that it may still be possible to be on a MEK inhibitors trial.

- The wife of a member came on to the discussion. Her husband has been allowed to go back to a dose of two pills in the morning and two in the evening per day of vemurafenib (V). It had been reduced to just two a day over the last three weeks because his QT interval had become longer. On the lower dose, his balance was affected and he was clumsier. Now, the QT interval is below 500. He also had to lower the dose of his mood stabilizer medication. Next week he is trying a different medication for the bladder. He has more tests and appointments coming up in July.