

Summary of ECD Global Alliance Internet Chat **18 Feb 2017**

8 Attendees

- Some of those who logged in did not contribute and are not familiar logins.
- A member on Kineret said that he doesn't know his BRAF status. He is to go back to Paris shortly for more tests. He had some nodules removed from his colon last December. He doesn't know whether these nodules were ECD tissue or not. He is from France, where he visits a small hospital that does not know about ECD. He wonders if he will have to be sent to Strasbourg (whose rheumatology department diagnosed the ECD). He is being treated for the intestinal problems in a local hospital, and he doesn't know if they make a connection with ECD. He will ask to have tissue samples examined for BRAF. [Editor's note: The ECD Referral Care Centers can be found at - <http://erdheim-chester.org/care-centers/> . Those patients who are being seen by medical teams who are not familiar with ECD are encouraged to have their doctors contact one of the Care Center physicians. If this is not possible, patients and family members can contact the Care Center physicians directly. There is a Care Center in Paris, with Dr. Julien Haroche as the lead physician who can help with ECD cases.]
- A member has seen his psychiatrist for the last time (at least for a while!) as she will be on leave, having a baby. He will be seeing another doctor in the meantime. His wife thinks that this last visit was a bit more positive than others have been in terms of his thinking and behavior. The wound on his back (like a bedsore) is still needing treatment, and now there is something to drain the wound.

When they got back from the appointment, they had a hard time getting in the house. They had come back seeing a beautiful sunset and then had to get up a pathway and up a ramp to the door, which was affected by the recent snow. He took a few steps and then he put his arm around her and she had to drag and support him to get into the house.

He was supposed to attend cognitive training class in the week, but there was a "blow up" between the next door neighbor (whose driveway is attached to the ramp - walkway) and the member's brother (who was parking there). The neighbor would not let him park there, while the member got into the car.

He is on a dose of two in the morning and two in the evening of vemurafenib (V). This is making him more physically stable and has improved his ECD lesions. He is also on a lot of other medications, and his wife thinks that a cognitive CD from the training is helping.

He last had an MRI in October and this showed some improvement. He is having a brain perfusion scan very soon. The instructions include a ban on caffeine, (e.g., tea and coffee) and no carbonated drinks for 24 hours before the test.
- We were given the link to a new article in the medical press about ECD: <http://www.bloodadvances.org/content/bloodoa/1/6/357.full.pdf>