

Summary of ECD Global Alliance Internet Chat **January 12, 2019**

5 Attendees

- Some members started the chat by agreeing that they were all “sick of this junk!” They each reminded the others of their present situation. One is now living in Michigan, sees Dr. Janku in Houston, is on two vemurafenib (V) in the morning and two in the evening (2 + 2), and is feeling well. Another said that he was diagnosed in 2008 and started on interferon, at the time. He switched to V last year, and this “wiped all his pain away!” He takes three to four V daily, but has found that four daily tends to cause diarrhea.
- Another member was on 4 + 4 V for six months, but this dose was damaging (“killing”) his liver. He was switched to dabrafenib and it isn’t having any problems now.
- Members advised all to sign up for Dr. Diamond’s ECD registry, if they haven’t already. Dr. Diamond’s email and link to the registry were provided.
<https://redcap.mskcc.org/surveys/index.php?s=NT4WHK7J7E>
Eli Diamond MD: diamone1@mskcc.org
- A French member said that he is also on a research registry with Dr. Haroche and has blood samples taken every time he goes to the hospital.
- The member with the baby came on. Both she and the child are doing well. Her daughter, 15-months old, started to walk last week. The child has seemed to notice that her mother has to hold onto the walls, so now she does too. Mum needs to use crutches outdoors and can't walk more than a few steps without help indoors.

Before she realized that she was pregnant, she had been able to walk short distances without support and only needed walking sticks outdoors. She wants to get back to that state. She is now taking 1+1 V. She had to stop her V when she discovered that she was pregnant. It was then that the disease returned. It was suggested that she should ask her doctors about dabrafenib. This is not as potent, but she might be able to take a higher dose of it.

- A member said that he wanted to go to the next conference in Italy, but his wife does not want to leave the family house. He only has to drive five to six hours to get to Milan, as he can go through Switzerland. He is still able to walk, and even run, but he gets pain all the time and doesn’t want to take drugs that are too strong. He tries to avoid needing drugs. He has physio twice weekly and uses plant medicine (which he regularly changes so that he doesn’t get used to them). He had met someone that day who said that he had to take therapeutic cannabis to “calm his suffering.”
- Members talked about wanting their doctors to go to the Milan conference so they could talk to each other and exchange ideas.