Summary of ECD Global Alliance Internet Chat
13 May 2017

8 Attendees

- A member said that she has spent quite a lot of time talking on the phone with her doctors. She has been taking just one vemurafenib (V) tablet for quite a while, but had not been feeling so good recently. Her balance was poor, she was much less active, and she had caught a cold. She has increased the V to two a day, but this hasn't changed things. She is now considering an increase to four V a day. Her last MRI showed some disease activity, with one new lesion. This is in her spine again, but this time it is higher up.

- A member on dabrafenib (D) is still on the full dose, although he is in remission. He has been on this for a year, but still takes three pills in the morning and three in the evening. He would like to be able to try 2+2. He says that the drug makes him feel tired.

- A member is getting pains in his fingers which trouble him every day. His wife often tells him to go to see his doctor to get some relief! He is on Kineret for his ECD. He manages to do a little bit of work in the garden, and takes care of his chickens. He told us that they have produced seven little chicks in 10 days.

- A member who has had long-standing shoulder problems is having surgery this week. Things had not improved despite having stopped her D in mid-April. She has now had a whole month off all ECD drugs. She is beginning to get more dizzy and her legs and knees are "saying hello in a big way". One nice thing about not being on chemo is that she doesn't have to completely avoid the sun! On D you are not supposed to be so sun-sensitive as when on V. When she was on the D, it was winter and early spring, so not too much sun to avoid or experiment in.

  She is changing her local doctors, leaving the private clinic that she has been going to, and going to the University of Kentucky (UK), Markey Cancer Center (only 5 miles away). She will continue to see Dr. Diamond and have Dr. Saeed (her new doctor) consult with him. She feels that she needs "research" closer to home. The Sloan-Kettering Pharmacy called her yesterday to see about sending some more D. She asked them to tell Dr. D's nurse to call her regarding the need for that. UK is a National Cancer Institute designate and they want her to be their "client" for a drug study!

  In January, she wrote up a copy of all of her doctors�much details, with their phone numbers and emails, so that each might choose to contact the other if needed. She is up to 15 doctors now, and is tired of being the only one that they all talk to. Her new doctor, Dr. Saeed, is her neighbor! He figured that out himself (he lives just around the corner from her) and tells the other oncologists at UK that she is his neighbor.

  She thinks that UK wants her to go on a D and T trial, but NIH wouldn't put her on it two years ago, because her biggest skin lesion was 8 mm and not 10 mm as needed for the trial. A recent biopsy was done on Wednesday of a lesion that was over a centimeter. She had two skin biopsies during the previous week and wondered whether she will test as BRAF positive again.

  Another member said that he had heard of people getting out of the V or the D+T trials, and then having relapses after three months or so. It was said that if you have been on V and D, then you can't be put on any kinase similar trials at all. Perhaps they are thinking of Mekinist or

COBI for her. At the moment she is just focusing on her painful shoulder. The UK clinic will be seeing her again in June.

Dr. Diamond emails her, but he hasn't done that for a couple of weeks. She wonders whether Dr. Saeed is communicating with him (she told Dr. Saeed that she would only start seeing him if he communicated with Dr. D!).

- The member from Norway wishes that there were knowledgable doctors local to her. Her doctors never contact Prof. Haroche in France, despite there being no problem with time difference. She recently talked to Dr. Estrada-Veras and sent her MRI pictures to the NIH.

- Communication between doctors is the reason that one US member goes to see Dr.s Garrity and Habermann in Minnesota. The thing that he likes about Garrity and Habermann is they talk to each other a lot - they are neighbors.

- The French member said that his results are transmitted directly to his local doctor and to his local hospital. From time to time when he is in Strasbourg, which is local, he pops in to say hello to the Rheumatology department and they are happy to see him. He also gives information to dentists when they care for him.

- A member, who is well after having V, said that when he was really sick with ECD, he "couldn't catch a cold, flu, or anything". He asked whether this could be because his immune system was "too strong". Now that he is better, he is actually having a cold!

- Members discussed whether they were going to this year's Patient & Family Gathering. One said that she had planned to go but things had changed and she would not be able to. The French member will be staying at home as he has an appointment in the hospital just after the event. Since it is going to be in New York, the member who lives there says that he "thinks" that he will be going!