Summary of ECD Global Alliance Internet Chat
28 Dec 2013

13 Attendees

- A member left a message saying that he was having " Big problems with our internet connection. Gets lost every coupla minutes, so we might not be with you all tonight. Happy New Year FTSOTP".

- One member had started to feel unwell on the previous night, but was feeling much better after some rest. She thinks that she might have eaten too much rich food during the holidays. She has had problems with dizzyness lately. The doctors are not sure about it, and think that it is something that she can handle on her own for now. On the bright side, she has been doing great at physical therapy, working on her shoulder and breaking up the scar tissue.

- One member started vemurafenib 3 weeks ago, and is having a lot of joint pain. December has been tough, with pain, and the associated inactitviy. This all started after one week of treatment. She has seen no improvement yet. She thinks that she is losing muscles, in her legs and arms, because she is so inactive. She is not used to being in any pain, and thinks that she has been lucky so far. Sleeping is very difficult, because the pain is worst at night. She thinks that she needs sick leave from work, for a little longer, because "everything is slow motion now". It was suggested that she try to "work out" a little bit, and to lift some weights so that she doesn't get muscle atrophy. She thinks that she needs to email Dr Haroche to see whether he has experienced other patients not feeling better after starting vemurafenib.

  It was also suggested that she might try emailing the doctors at Sloan too. A member said that Dr Diamond is "great about emailing and soooo nice!!!".

- Another member wonders what he has "to look forward to" when, and if, he goes on vemurafenib. He is still waiting for his results. He has no neuropathy, but unbearable bone pain, and is on no treatment at the moment. He has lots of trouble even trying to put any weight on his legs. His last MRI showed that the ECD had spread past his knees to his upper legs, in a matter of a couple of months. The interferon hadn't worked and he is now on nothing. He is "in limbo again." His Doc is trying to get his insurers to cover the cost of vemurafenib, but it is not looking too good. His problem is that there are no trials on the west coast, where he lives. His Doc has sent emails out, to try to figure out where to go now, but after 3 weeks he hasn't had any responses. He has contacted Dr. Juvianee Estrada-Veras at the NIH in Bethesda, MD already. Dr E-V has the tissue block, from a bone biopsy done about a month ago, and he is doing the BRAF test himself.

- A member has tested negative for BRAF, so he can't do the study at Sloane. He also found out that he has pretty bad neuropathy. He has started on Lyrica but seems exhausted lately. He is on just a small dose. This effect been noticed in another member's husband when he took Lyrica too. He had neuropathy in his feet during chemotherapy for cancer. He now has it in his hands.

- Members discussed the taking of Kineret. This is a daily injection, and is usually painful. A number of members take the injection fluid out of the refrigerator, a short while before the injection, so that it can warm up a bit. Some put an ice-pack on the site where the injection will be. This can reduce the pain at injection time.

  A member, who had had a lot of bone pain, told us that she had tried many medications, with nothing working until she used Kineret.

  Another is taking Kineret for bone pain, and methotrexate for her joints (she has rheumatoid arthritis as well as ECD) and these have really helped. She occasionally has bone pain now, but not as bad or as often as before.

- A member is concerned that her husband's doctor is as concerned about his illness anymore. He has been on interferon for 3 months. The doctor has changed the interferon from 3 times a week to once weekly. There is a form of interferon, pegylated interferon (Brand Name Pegasys), that remains in the body for longer, and is only injected once a week. This form often has less side-effects. It may well be the case that the doctor has just changed the form of interferon.

- A member has been on the thrice weekly interferon since '07. His Doc is not willing to change at the moment, "Don't fix what ain't broke". This member has been stable for at least 5 yrs. He can't work because of his balance problems. His kidney biopsy was negative for BRAF.

- A member said that his son had used interferon, but had not gotten good results. He started on Gleevec about 2months ago but this is also not agreeing with him.

- A member FTOSOTP came on towards the end. He had got the time wrong again! He will, possibly, find out on Monday whether he has funding for vemurafenib. He will try to be here at the right time (8pm in UK) next week.