

Summary of ECD Global Alliance Internet Chat

18 Jan 2014

12 Attendees

- A member who has had a few weeks of vemurafenib therapy left a message to say that "Things are really going great." She has no pain now, and lots of energy, and couldn't be on the Chat because she was going out to the movies!
- Another member also left a message. He has just had heart and brain MRIs. He has been told that he has several areas of involvement on his heart, and a very large one at the back. The radiologist was quite shocked at how much involvement there was, considering the small area that he scanned! He is due to start treatment with vemurafenib next week.
- A member has had problem with 2 of his teeth recently. He can't afford to get them pulled at the moment. He is soon to restart vemurafenib treatment. He had to stop this when he developed acute pancreatitis. A member asked whether they could be "accidentally" removed while he was having his treatment. It was suggested that he ask in the hospital, to see a social worker or a patient advocate, and to tell them about the teeth issue, and that it could impact his treatment if he was to develop an infection. They may be able to help him find someone who would do the extraction pro-bono...or even an oral surgeon who would do the extraction in the hospital as an infection avoidance procedure. The member doesn't know whether the teeth problem is related to ECD, or to the medicines that he has been taking. Another Chatter has also lost a tooth, and a member, who was not on the Chat tonight, has had many tooth problems.
- The member about to restart vemurafenib is not on a trial (there aren't any on his side of the US) and wishes to know where to go if he develops side effects again. This is a difficult situation as his doctor should be one who is managing his care. However, because his doctor is not experienced with vemurafenib treatments, the patient is looking for additional support. He will need to be monitored closely to see if something not so good is happening, BEFORE it becomes difficult. It was suggested that his doctor should be in contact with the MSKCC docs and Dr Estrada-Veras before the vemurafenib is restarted. Both the MSKCC, and NIH doctors are willing to talk. However, the doctors at the NIH and MSKCC can't be responsible for a patient they have never treated. The patient is particularly concerned because the interferon didn't work. He tried vemurafenib, and got Acute Pancreatitis, which he thinks has only happened one other time, and, in that instance, when vemurafenib was reintroduced the Side Effects were worse, and happened faster. His doctor is willing to restart the V. Hopefully there won't be a repetition of the bad effects when he restarts at a lower dosage.
- Kathy told us that she had just returned from a visit to MSKCC and NIH. MSKCC continues to see good results with the vemurafenib treatment, and the trial is progressing well. They are hoping more patients will be able to join the trial, and the NIH is working hard to open a trial for dabrafenib (BRAF-inhibitor) and trametinib (MEK-inhibitor).
- There may not be any published updates, because they cannot publish any data until the trial is over. They did say that they have enrolled a number of patients. A couple of patients have had to be taken off the trial, due to issues, but all the rest continue to do very well. The joint paper that was discussed in San Diego is also in work. A first draft is under review by those who were in attendance at the Symposium.

- A member asked about the travel needed to be in one of these trials. One of the good things about the trial that the NIH is trying to start is that they would cover the travel and drug costs! However, it might mean that you need to stay in the Bethesda area for the first month of treatment (with the NIH paying for lodging and food). And then return every two months after that. The study design is still in work, but this is the latest thought of how it might turn out.
- A member is having trouble getting help to pay for her peg-interferon treatment. She was asked whether she had contacted any of the patient assistance programs. Kathy offered to send her the names of some organizations that might be able to help. If that doesn't work, her doctor's office may have to help her to apply for a compassionate allowance. A member, who has used patient assistance for Kineret for one year, has to re-apply.
- Our member, who is an artist, had had a good week painting, but was not able to walk much as her legs were swollen and hard. She is a bit reluctant to try vemurafenib because of the sun problem (she spends a LOT of time in one of the Greek Isles!). Dr Pete Hillman, in Leeds UK, wanted to try methotrexate. She had thought that this was beginning to help, but as she has had a lot of pain and swelling this week, she is not so sure. Maybe the Doc will up the dose again. He did tell her that it takes "quite a while to kick in". She commented on how lucky those in the UK are with the National Health Service. She has "nothing but praise" for the help and treatment she has received, and it is all FREE Of CHARGE! She is hopeful of meeting another UK member in the not too distant future. This member also sees Dr Hillmen.
- A US member joined the Army in 1967, and the Department of Veterans Affairs pays for his interferon.
- After the Chat finished a member came on to explain that she had been at a baby shower, and that that was the reason for her absence. She has been doing well apart from having some bad dizzy spells.