

Summary of ECD Global Alliance Internet Chat

14 Mar 2015

7 Attendees

- One of these came on late when we had gone, and two of the US Chatters were already "at it", when a European "looked in", and found them chatting away. Although the chat wasn't supposed to start for another 30 minutes, according to the European's clock! Time changes in different regions must be the reason for these mix-ups.
- A member came on who has not been on the chat for a while. He was not at home, and was trying to use his phone.
- A member in the vemurafenib (V) trial in NY said that he was doing OK and going there monthly.
- Some members spoke about visual problems. Double vision was talked about and one said that he had had some blurry vision and light bothered his eyes, but he is doing better now.
- The member who was using his phone to chat said that he has been off Kineret for almost a week now. His doctor thinks that he may be OK without it.
- A member has been diagnosed with osteoporosis, due probably to the long courses of steroids that he has taken over the years. He fell in the bathroom a few months ago and broke a rib, and his bone densitometry scans show low readings. More tabs!!
He had been treated with steroids when his chest got really bad. He had once needed 11 days on a ventilator and had got close to needing one on another occasion. He also took steroids when he started his methotrexate treatment.
On a much brighter note, he also found out this week that he has joined the "Remission Club"! His recent PET showed that all the previously active areas were quiet, and that there were no new active areas. He has never had his BRAF status assessed, and has never been on V. He has been taking methotrexate (40mg once a week) for the last few years and has been relatively stable. He will be continuing on this drug indefinitely, and having a PET just once a year providing that he stays well. All the treatments add up to more than 5,000 tablets a year! This figure is pushed up a bit by the methotrexate because, although it is not a large dose, in the UK you can only get the 10mg size from a hospital pharmacy. Ordinary street pharmacies can only dispense the 2.5mg size. $40 = 2.5 \times 16!$ So, methotrexate daily pushes up the numbers! It is a good job that all 5,000 are paid for by the UK National Health Service! If you are under 65, over 16, and not unemployed then you have to pay a small amount, but you pay nothing if you are older or younger. Also, there are a few "Star Prize" illnesses (such as diabetes or epilepsy) for which you get all your medicines free,

and medicines for all the other things, that go wrong with you, are free too! All investigations are free, which helps a lot when you have endless MRI and PETCT scans.

He was asked about the side-effects of his methotrexate. He doesn't get any! His doctors do not know how the methotrexate is working. It is an old (and CHEAP) chemotherapy drug, so perhaps it is just keeping the "bad" cells down to an acceptable level. At an even lower weekly dose, it is used as a successful treatment for Rheumatoid Arthritis.

He is now down to a follow up only every 3 months. So it looks like methotrexate "did the job". A member on the V trial was interested because he is also in "remission", and will be in need of a drug for maintenance. If he comes off the V trial he won't have access to V anymore.

- A US member said that, although his insurance is considered to be "pretty good", he still has "a ton of bills to pay". He is still paying for the very first MRI that he had done, before he went to Mayo. And he is now at Sloan-Kettering.
- There is a Canadian member who is BRAF+. He had been advised to contact the National Institute of Health (NIH), to see whether they will take non-US citizens onto the V trial. He has sent them all his paperwork, and is waiting for a call. He is currently not taking anything aimed at the ECD, but he does have to take anti-rejection drugs because he has had a kidney transplant (Prednisone and Cyclosporin).
- A member has had a very sore groin for the last 2 weeks. He hoped that it would get better with rest, but it hasn't. No-one else had had a similar problem.
- A member, who has been on V for 15 months, is trying to reduce her dose. She is now on just 2 a day. She had her last PET a year ago.
- One member told us that interferon had worked for him right away, and he has been stable. He goes for follow up twice a year and has 1 or 2 MRI scans a year. Although the last one that he can remember having was at NIH in 2011. There has been some discussion as to whether he should try V. But people aren't keen ("Why fix what ain't broke!!").

The other members were surprised to find out that he still doesn't know if he is BRAF+ or not. He said that he had never got the results from Dr. Estrada-Veras. He said that he would "give 'em a call" and "try to see what's up".