

Summary of ECD Global Alliance Internet Chat

20 Dec 2014

5 Attendees

- Not very many chatters this week, and they didn't Chat for too long!! Christmas shopping was blamed for people's absence.
- A member said that he will be having a PET-CT scan in the near future, to see whether there is any active disease. If not, the doctors can say that he is in "remission" (Note: there is no agreed upon definition for remission in ECD at this time). He wonders whether the doctors will make any changes to his methotrexate treatment. This is taken just once a week and doesn't make him ill. He does have to take 16 tablets at once, as he needs a dose of 40mg, and each tablet is just 2.5mg. The manufacturers do make a 10mg size tablet, but this can only be given out from a hospital pharmacy, and not from a community one. They can only dispense the 2.5mg size.
- Other members mentioned when they next have check-ups or scans.
- A member came on who has been on Vemurafenib. He stopped taking it in September, and is on no medication for ECD now. He had started taking it in January 2014. After 9 months, it didn't seem to be having any positive effect and his doctors worried that it was damaging his kidney. His doctor thinks the disease may have burned out, or at least be in some form of remission. He will be going in for a scan soon to make sure that this is the case.
- There was another member on the Chat on V. She has been on it for over a year, now.
- The wife of a member who doesn't speak English came on. He had a problem with one of his little toes. It would not heal and had to be amputated. The foot has now healed, but he fell sometime after the operation and hurt his back. His medication has been changed, instead of interferon, he is now taking 2 x NEORAL 100 Mg (cyclosporine).
- Finally a message was left after the Chat. A member told us, that she has been doing pretty well, apart from some back pain and pain in her shoulder that was operated on fairly recently. She was told by a doctor that her blood work showed that some of her hormones are "off count" a little. The doctors have given her a diabetic diet to try. [Diabetic diets are usually given when blood sugar is high. A diabetic diet is perfectly healthy. There is just less sugar in things!]