Summary of ECD Global Alliance Internet Chat

29 Oct 2016

7 Attendees

- Before the Chat started, a new (to the Chat at least) member came on. He is in Kansas City and has been unable to participate because of work, although he said that he has "lurked" in the Chat Room a couple of times. He now receives the summaries [Hooray, another reader!]. He is going back to the National Institutes of Health (NIH) for his first follow-up on the dabrafenib (D) and trametinib (T) trial. So far, he has been doing well, with only minor side effects. He said that he had started an online diary of his experience with ECD and the NIH trial; www.joseflacy.wordpress.com is the blog's web address. He invited members to look at it and send feedback. He created it to keep friends and family apprised of his situation, and to give the next person an indication of what to expect. He said that, "It's hard to believe it's been a year since a radiologist took a guess on a scan". He thinks that he is "one lucky SOB!"

- A member who has been on vemurafenib (V) for some time told us that she has been taking just one tab a day since early October. She is having a scan soon, after a long gap.

- Methotrexate (MTX) was discussed. On the previous week's Chat, a member had told us that a doctor spoke of a patient whom came off of D and was now on MTX once a week.

  A member on the Chat said that he had been on MTX once a week for a few years now, and he is in remission. There is no plan to reduce or stop this, since he has no side-effects and remains stable. MTX is MUCH cheaper than V, as it has been around "forever"! In the UK, a month's treatment cost the sterling equivalent of $8! This member never had V because it "hadn't been invented" when he was first ill.

  Methotrexate comes as pills, and it is also widely used at a low-dose in rheumatoid arthritis, but the dose is much lower (less than 10mg a week, while our member is taking 40mg a week). Because it is not an "approved" drug for ECD, insurance companies in the US may not pay for it, but it's still a LOT cheaper than V or D!!

- A French member has been using Kineret for two months at a cost of 1,000 euros per month. You would still need to be treated, and get into remission as the first priority. The member on MTX had interferon and 2CDA therapy initially, but both failed. He was then in remission with prednisolone (another inexpensive drug) and a higher MTX dose.

- A member on V said that she had dropped about 20 pills into her sink the previous week. She happens to be seeing the local oncologist this week. Her dizziness is worse. She currently is prescribed one pill in the morning and one in the evening of V. Her local oncologist can order a brain MRI in Lexington and the insurance will cover it; but PETs are ordered by Dr. Diamond. Her insurance doesn't like to cover the cost, and Memorial Sloan Kettering has to bear it. Her case is going to be presented in February at a JAMA dermatology conference. The doctor at the University of Louisville missed her ECD diagnosis. The focus there was on another skin disease.

  She said that she was going to make something of her trips to NYC. Her daughter and son-in-law, who will meet her and her husband there, have bought some *Wicked* tickets (a Broadway show) for December 15!

She has had acupuncture three times in the last 10 days but with no relief from joint and shoulder pain. She also goes to a warm water pool a couple of times a week to exercise. This doesn't help with her hand problems; she has developed 2 trigger fingers.

- Another member also goes to a pool to help his hands. He does exercises in the water with a stick, or he shakes his fingers for light relief.

- Another member has tried a therapy where you "float in a tank" for one hour. She said that she felt great.