

Summary of ECD Global Alliance Internet Chat

06 Dec 2014

5 Attendees

- Only 5 Chatters this week, but a LOT of Chatting!
- In the UK, 3 members met up for lunch. They all attend Professor Pete Hillmen in Leeds. They now want to be known as "The North of England Chapter of the Global Alliance". There is a picture of them on Facebook.
- A member asked about other members in her area. Kathy publishes a list of where members live (in the US by state, elsewhere by country). This can be made available to anyone, but she can't give out specific information about individuals in the organization. However, with permission of all parties, she can make an email introduction.
- A member said that she was doing pretty well but is getting tired easily. She is on steroids at the moment due to her macular edema and vision problems. She is just starting her 4th month on Anakinra. She has to go for an MRI of brain/orbits and a PET scan next month. She sees Dr. Diamond. She is not looking forward to taking a trip to New York in January!!
She is BRAF negative. The doctors think that the edema is related to the lesions in her orbits. She was originally diagnosed with Rosai Dorfmann Disease, and treated by Dr. McClain. The NIH said that, because she had RDD, they couldn't take her for the ECD study. Now, she is going to Sloan where a second biopsy (of the tibia) favored ECD. She has a local oncologist working with Dr. Diamond. Dr. D. is always available to answer her questions.
- A member has just come back from Sloan-Kettering, after a follow-up with Dr. Diamond. He is in the vemurafenib (V) trial. Every month he has blood samples taken, checks weight and height, has EKG (sometimes), gives urine samples (for BRAF levels), etc. Then every other month, he has a brain MRI and full body CT/PET. He doesn't think that he is going to get any better, but he needs to stay on the V to maintain the improvement.
- Kathy told us that she and Jessi had been in Houston on the previous day, looking at hotels, trying to make a selection for where to host next year's conference. She is hoping to be able to make an announcement in the next couple of weeks.
- A member, who runs a cooking group (a fancy way of describing a bunch of blokes who prepare, cook, and eat lunch), has found some new premises after the resource center, that he had been based in, went into voluntary liquidation (that's a polite way of saying bankrupt). He has now got the use of some space in a building owned by the local council and has a "covered market" in it. The group is "good fun" but the new spot has big windows. "It's like cooking in a store window!" People passing by sometimes recognize one of the group and come in to chat!

- A member, who has been on V for a year, is on a dose of 1 in the am and 2 in the pm. She started on 2+2, but this was too much, and 1+1 was too little. She is going on a trip to Barcelona soon. She was told that the Las Ramblas area is fantastic, but you need to be watchful for the pickpockets, etc.!
She is doing well with lots of exercise, and other appointments. She is in "remission" now, with no more growths. She is continuing on the V (after she had told her doctor that the ones who had stopped the V had relapsed!). Her doctor had suggested that maybe she only had to see him every 6 months, since she is stable, but she "convinced" him to keep it at every 3 months!
- A UK member also only goes to his doctor every 3 months. He isn't on V, and won't get it unless he gets significantly worse! He has not been BRAF tested and needs to develop a "nice big bad bit" for the doctors to stick their needles in for a biopsy! The member hopes that this will never happen!
- Kathy asked whether anyone had any specific topics that they thought should be included in the ECD event in October 2015. The Alliance is about to begin inviting speakers. She would like to be informed if there any particular topics that members would like covered.
Then she asked about members' plans for making and posting an ECD Hope Angel on their Facebook page. A member told us that she didn't do the Hope Angel, but she did post information about the disease and how it affects her. Everyone said they'd donate, but she only had one person donate "in her honor". The funny thing about donations is that, sometimes, it takes people a long time to "get around to it." The important thing is that people are made aware of ECD, and its effects.
- Skin lesions while on V were mentioned. A member on V said that he had some moles that were growing very fast. Two had been removed the previous week, to be safe. He is expecting that he will be seeing the dermatologists more often. The Norwegian member who has been on V for a year now gets checked every 3 months by a dermatologist.