Summary of ECD Global Alliance Internet Chat
7th Jun 2014

9 Attendees

- A member told us about a machine that he has, made by Tefal, which takes a lot of the difficulty out of jam-making. In goes the fruit, sugar, and water, and after 30-45 minutes of bubbling, out comes jam!

- Vitamin B complex has been started by one member, and he feels that his energy levels are a bit better. Another member gets a shot of vitamin B-12 each month. He can't tell any difference between having the shot, and not having it.

- Members discussed their impending visits to the NIH. The members who will be going first agreed to pass information onto the others who will be following. Those who have already attended NIH said that the time will be enjoyable. They said that they were really treated well and the NIH staff were very kind. A member said that "it feels good to contribute to the research in a small way".

- A "longstanding" V (vemurafenib) patient has her 6 month checkup soon. Things are still improving. She is walking more on her own, and is able to go faster and further.

- Attendance at the September meeting was discussed. One member has FREE accommodation lined up! A former diving pupil of his, lives right up the road from Bethesda. He made the offer to put them up. Their daughter, who has ECD, and her husband will be staying at the Doubletree.

- A Belgium member came on. He has had a diagnosis of ECD for 1 year and he and his wife don't know whether the interferon is helping. At present he can't walk because of his foot pain. He started with thrice weekly injections, and changed to 1 a week after 3 months. [Editor's note: Regular interferon is usually administered 3 times per week and pegylated interferon is usually only administered once a week.] They think that he is BRAF negative, but wonder if this is really the case (he is the doctor's first ECD patient). A scan was done 3 months ago, so now they have something to compare with. In August he will have a second scan.

- A new Chatter came on, a female patient from Bahrain. She had ECD diagnosed in 2012, but had had DI (Diabetes Insipidus) since 2008. She follows the Chats, but attendance is difficult due to the time difference.

  She flies to the United States for her hospital visits, and is seeing Dr. Janku. Her first problem was DI. She is a Neuroradiologist (a physician who specializes in taking images of the nervous system!). She has some bone and lymph node involvement. She tries to think of this disease from the viewpoint of a patient, and not a doctor. She concentrates on the positives. "If I think of all the negatives I get depressed".

- Another member said that he had been lucky in having a close friend who is a psychologist. He has helped them a lot.

- After the chat had finished a message was left. A member apologized for missing the chat. She had been helping her father work on an old (1963) Ford Ranchero. They had finally got it to start! She has been having a lot of pain in her back and in her right shoulder. There is limited movement at the shoulder, and she hopes that her rotator cuff is not torn.