Summary Of ECD Global Alliance Internet Chat
21Dec 2013

10 Attendees

- Before the Chat started a member FTOSOTP left a message to say that their internet connection was misbehaving. And after the Chat had finished another member FTOSOTP left a message to say that he has just got his official disabled parking badge. He is still waiting for news on his chances of starting vemurafenib.

- A member said that she was not feeling too good, and was lying in bed with a chest infection. She has also been breaking out into sweats. She was told by a nurse that it was a side-effect of methotrexate. She also has mouth ulcers. She said that "Side effects do not seem to be on the top of the doctor's list of advice". A member told us that her husband, who has ECD, used to wake up, with high temperatures, for no reason. There is a paper, on the new website update, about fevers of unknown origin in ECD. (see: http://www.ncbi.nlm.nih.gov/pubmed/24228820)

- Another member has also been having attacks. He has woken up, a couple of nights, just covered in sweat, and with a fever of 101F. He wonders whether this is because he isn't on interferon any more. He was on Pegasys (long lasting interferon) and had flu-like symptoms during the first couple of weeks. Also, around the injection sites, his skin was red, very irritated and dry. No amount of lotion would help. Recent scans have shown that the disease is affecting more of the bones in his legs. His markers never went down, and when he had his quarterly MRI, it showed significant progression in his legs, and so interferon was stopped. To find out that the interferon hasn't helped is not good. He is "in limbo" regarding the next step in his treatment. Dr Estrada-Veras has had his tissue block for two weeks, and he is waiting to hear from him.

  He has been troubled with blurry vision, and also with his balance if he tries to move quickly. He is not very mobile, having lots of bone pain from his legs. This makes it difficult for him to put weight on them. He is using crutches all the time. He is already taking 2 painkillers, but they barely help at all. If he tries to move quickly, he loses balance and steps "like there is nothing there". He hasn't fallen much, but even one fall is one too many! He also realizes that his strength is much less than before, and he has difficulty getting up. He has a hard time with shopping. He has to sit in the car if he can't find a cart in the stores to ride.

  His doctor tries, but he has no knowledge of ECD. He seems to be having trouble getting knowledgeable doctors to communicate with him. It was suggested that, his doctor should contact another doctor listed on the ECD website. There are many listed, and other docs have used it as a source for contacts. Many members had the experience of being the only ECD patient in their area. Members said that they liked to be in contact with others in the ECD "family".

- A member has just been to Sloan Kettering, and has had a "good result" on his brain scan. No brain lesions were seen, just a "teeny bit" lit up on PET, where old brain tumor was (old injury sites can still light up). He takes Pegasys once a week, and is suffering from the flu-like side effects. He tries to push on, not letting it interfere with life. He has been shopping, but he had to sit most of the time. Despite the interferon, his markers are all still high. He was diagnosed this August, but has had symptoms for about 3 years. His wife is finding that ECD tends to be "the center of our universe”. She finds that she can get away from ECD by working or reading, and losing herself in that. It was agreed that it was very important to make time for you.

- Another member has started taking her husband, who has ECD, to the gym. He has been working with a personal trainer, and she thinks that she is going to start working out there, too.
- A member, who had used interferon, found that it only helped to reduce the bulging of the eyes. He then tried many forms of chemo, and other drugs, eventually finding that Actemra took away all of his bone pain. Kineret helped with the bone pain, too, but the Actemra seemed to help stabilize things.
- A member, who is taking Kineret and methotrexate, said that this combination is helping with her bone pain and fever.
- We have three members who are currently awaiting the results of their BRAF tests. One of these is a Spanish speaking member. He was diagnosed 3 years ago, and is on interferon, but it is no longer working.
- Diabetes insipidus was discussed. One member has this controlled with a small dose of DDAVP. Another uses a nasal spray, twice a day. He needs to use it at exactly 12 hours apart, or he “knows it”.
- A number of members have found that taking prednisone affects their blood sugar.
- Difficulties with the US SSI system were discussed. This is an ongoing difficulty. Food stamps being cut, and children having to be removed from wills, so they don’t inherit. If they do, they will just have the same amount deducted from their benefits.
- A member has been very dizzy lately, and falling over when walking, because she loses her balance. She also had leg pains while playing softball (!), but her medicines helped with that. She has managed to deliver presents to all of the dogs that she walks (her job is a dogwalker). She said that she had only actually fallen twice, but she often walks into things, such as table at a restaurant. She once fell into her closet, and had to get up from under the clothes!