

ECD Global Alliance

Internet Chat Dec. 29, 2012

8 Attendees

- A new member went onto the Chat before it had started. He has been recently diagnosed with ECD and his oncologist has prescribed Peginterferon Alpha 2A. His problem is that his insurance only covers half of the cost, and interferon is, as we all know, very expensive. He has been looking for financial assistance from a foundation. He wishes to know where he should look.
- Last week a member came on before the Chat, saying she was from the UK. She lives less than an hour away from another member in the UK.! That is, when she isn't on a Greek island, where she spends 8 months of the year!!
- A member has been told that she should start chemotherapy, in the next week, which is a shock. Other members told her about their chemotherapy experiences. She has got ECD in her lungs. One member said that, the ECD had been in his lungs, too, and that he ended up on a ventilator for 1 ½ weeks. But he is now able to play his trumpet (the music teacher might dispute this!), which takes a bit of blowing to get a note!
- Different experiences with chemotherapy were then discussed. Some chemotherapy drugs make you feel very ill, and some seem, to be well tolerated. A member, who had a course of cladribine, (that's 2CDA in US speak), as injections under the skin, said that it had not been difficult (the member said that the taxi rides had been the most difficult thing). Other members were also about to start chemotherapy, one for the second time.
- A member enquired about health insurance. Two members were from the UK where the National Health Service "picks up the tab".
- Then, problems over Christmas were discussed. The brother, of a member, had got Christmas lunch stuck in his throat. He spent three days in hospital, and had a camera down his throat, which sorted him out. One member told us that, last year, he had coughed himself unconscious, while playing Monopoly with my wife and in-laws! He was just about to land on Mayfair, and his wife had a couple of houses on it. This may have had something to do with it! A member, who had given his wife the board game, Othello, asked whether this would be safe! (Summarizers note: sucking the pieces should be discouraged!)

- A member asked how we fill our time. This member said that, they were “still in so much shock. This is not fun, to think your life is just drugs and pain”. Happily, the member is able to take enjoyment from being with her new grandson. A member has previously written about “Planning Your Day”, in the ECD-GA newsletter, and a copy will be sent to the, enquiring, member.
- A member has spent some time in Tennessee and bought a pre-manufactured home, to be put onto land, owned by his son, and then, his son, can keep an eye on him! This member is one of those who will restart chemo soon. It worked for him before. So we are optimistic!
- A member, whose son has ECD, told us that he bit down on a piece of candy, and broke off a good tooth at the gum line.
- A member enquired whether anyone had managed to stop their medicines. One member had stopped all of his, another member is now only taking vasopressin at a low dose (for Diabetes Insipidus, not for ECD itself). Another is just taking one drug for the ECD, and that is methotrexate taken only ONCE a week!
- A member told us that 6 months of interferon treatment had not helped, and so 2CDA may be the next step.
- And, lastly, we were told that one member still needs to take all his medicines.
- The member who is about to start chemotherapy has a port already inserted into her chest. The doctors have said that only one person has used 2CDA, before. The Chatters said that this was not true overall (although it might be true at a particular hospital).
- A member told us, that when her son was on 2CDA, all foods had a metallic taste. He ate a lot of chocolate donuts etc and drank Ensure. He is now doing well.
- Members wished each other a Happy New Year!