

Summary of ECD Global Alliance Internet Chat

8thJun2013

7 Attendees

- A member was having some difficulties with arranging someone to look after their mother, who is "in bad shape". It is a long drive to get to see her. Another member said there were similar difficulties regarding his father. Both of these parents are over 80.
- A new member came on whose son is on his 5th day of Kineret shots. She asked whether anyone had any experience of this, but none of the other Chatters online for the session had any experience with Kineret.
- A member told us that he had just started Cladiribine (2cda) treatment. The regime is injections for 5 days in a row, and then a month off, to be repeated for 6 months. This is the same regime that another UK member had, a couple of years ago. Another member told us that his daughter, who has ECD, but is now in remission, had also been treated with 2cda (Cladiribine), for 5 days a month, for 6 or 7 months. But she was pretty sick the whole time. She is now doing "well enough". The only medicine that she takes now is a low dose of DDAVP. She has tried to do without this, but found that this was still needed. She, recently, went shopping, for summer clothes, with her sister and Mom. And her new husband went along too. Another member said that the husband "deserved a medal". But the member who had told us this story (and who is also the husband's father-in-law!) said that "He needs them all to keep him in line."!
- A number of members then told us of the difficulties that they had with balance. This seems to be a common problem.
- A member, who is flying to the Global Alliance conference from Australia, in the Fall, will be on a round-the-world trip. He will, probably, be visiting some other members, and they are going to exchange information before then.
- A member mentioned the BRAF test. His wife does not want him to have it at the moment, as he is stable, and she is concerned that yet another drug might be added to his treatment.
- Members then discussed the number of tablets that they had to take each day. One is taking 4 medicines a day, and he also takes approx 10 supplements. Another takes 9 tablets a day, and 25 on Tuesdays! And another takes 22 a day (and a "bonus" extra one on Mon, Wed, and Fri!). A member, whose wife had ECD, said that they turned preparing, and taking, all the tablets (15 in the morning) into a lovely morning ritual!

- One member, who hasn't got ECD himself, is supposed to be "healthy" and he takes 2 fish oils, 1 synthroid (hypothyroidism runs in his family), 1 atorvastatin (Lipitor), 1 vesicare, and 1 aspirin!
- A member uses a Testosterone rub. If he forgets to use it, his wife will only bring it to him if she wears rubber gloves. For some reason, she doesn't want "to get hairy"!
- Finally, a member told us that he had once missed taking a few days of one of his medications. This had led to a lot of nasty symptoms, and is not to be recommended.