

Summary of ECD Global Alliance Internet Chat

3 November 2012

13 Attendees

- A member boasted that he “had a hot date with a beautiful woman today”, so he would be “otherwise engaged” tonight. But this week, has been marked by balance problems, and falls.
- Another member wanted to let us know that his daughter had a good visit with one of her doctors at Penn. This doctor, Dr. Mark Levin, had taken the time to read up on her case (the paper authored by Dr. Stacy Pineles et al).
- A member told us that in a week from now he will be in Houston, for the first in-person meeting of the ECD Global Alliance Board of Directors. The highlight will be a symposium of several of the doctors working on ECD to see where they are going. The member is struck by the variety of treatments which are being used to treat ECD. This member had been diagnosed in 2001, which was the same year in which Dr. Kurzrock found interferon to be effective in ECD.
- A member, who has recently died due to ECD, had a period of nine years during which the ECD appeared in three different ways, and three different treatments were used. The final treatments were not able to control the ECD lesions. 2CDA was the last drug tried, but it was no more effective than high dose methotrexate, double dose interferon, azathioprine (Imuran), or tamoxifen. The only thing that slowed down progress was dexamethasone, but that did not stop, or cure the ECD.
- Dr Kurzrock has recently moved from Houston to San Diego, and she will participate in the symposium, by teleconference.
- Members compared the types of specialists that they were seeing for their care. These included an oncologist, haematologist, and a paediatric haematologist.
- A member was ordained as a permanent deacon in his church last week, and so he missed last weekend's chat session, because he was running family out to the airport.
- A member has just had a CAT scan, and X-rays taken of his legs, at his annual review. His leg bones “looked like Swiss cheese”, and are hard and brittle. Then, the subject of changes in bone, which are due to ECD, was discussed.

One patient's bones had been described similarly. They had looked like inverted Swiss cheese - bone with darker/denser holes/lesions all over the place.

Another member told us that their bones are extra hard, and some areas are extra thick. There is even bone growing around one of the spinal vertebrae that causes severe pain.

- We were asked whether any of us had reached a stage where we were not taking anything for ECD and were we stable?
 - Most of the medicines that one member takes are for pain.
 - Another had been stable for two periods of time, but never on 'nothing for ECD'. When stable, life was normal in most ways, but there was ongoing, and worsening, bone & joint pain, and low energy levels. Vision was slightly impaired, but glasses worked well.
 - Another wasn't taking anything for ECD for about a month, because they had a strep throat infection and juvenile xanthogranuloma started getting worse.
 - Another member is just taking a vitamin and DDAVP. The DDAVP is for diabetes insipidus (DI), a water management problem (not diabetes mellitus, which is the sugar management one). The member is in pretty good health, but has trouble walking, and with balance. One of the early signs of ECD can be DI. When the member was in her teens and early 20s, she'd drink nearly a gallon of water a night. She'd take a container and put it next to her bed!
- DI can show up 10 yrs. before any other symptoms show. It was the first sign for a number of members.
- We were told that daylight saving time ends in the US on this Sunday at 2:00 A.M. The European members turned up an hour late. Their clocks had gone back an hour last week! All will be right next week when the US has changed as well.
- One European is going back to the NIH, for her second visit, in just 3 weeks time.
- After the Chat had finished, a new chatter came on. She was worried because it seems to her, that her son, who has ECD, has given up all hope. She asked whether any of us had also gone through this.