

Summary of ECD Global Alliance Internet Chat 05/01/2013

10 Attendees

- Members all wished each other, and all Alliance members, a Happy New Year!
- A member told us that he could predict the weather, because he gets headaches when rain is approaching!
- Members briefly said how they were, at the moment. One was stable, one had a strep throat infection, and one couldn't get any work done, because it was raining in Tennessee!
- Reports on visits to the NIH were made. One member said that "it was a great experience". This member had seen a lot of doctors, and had had a lot of tests. Cysts were found in the lungs, some skin lesions were biopsied and irregular bone marrow was confirmed. There was, also, some short term memory loss. This may be due to medication. The comment was made that this must make for some difficulties at school! The member told us that school has been a struggle, but a note for school has been provided, to see if some extra help can be given. Interferon seems to be helping with the skin lesions. Zometa (zoledronic acid) treatments are being given, every 3 weeks, for the bone pain.
- Another member admitted to also having short term memory problems (relating to what his wife has asked/told him to do!).
- A member, who is currently in remission, doesn't have any memory problems. Her father said, "She seems to be sharper now than ever." However, this may be due to the fact that she has lost her sight, so that she has to concentrate hard on many things, so as to keep her bearings. She had recently, been to the NIH, and had been very impressed with the hospitality, and with the food! This member was at the NIH at the same time as another, who was making her second visit! They had met up the year before, so they met up again.
- Members had "got through" the holidays OK. One member said that his "favourite gift" was a new house! He was asked how Santa had got a new house down the chimney. "He worked at it." Was the reply!
- The wife of one member has become allergic to gold, and is having the stone from her engagement ring reset in silver. The member, himself, had

been given a new coffee-maker, that makes whole pots of coffee at a time. As far as he is concerned, "Coffee is the drink of the gods!"

- We were reminded that one ECD sufferer had had her problems mostly cleared by 2cda, followed by interferon. She has been stable for the last 2 years, and has been told that she is in remission.
- A member, who is about to restart 2cda therapy, is hoping that it will help with his pains. He has been clear of ECD for 9 years.
- Some members told us where they were living. They were from Red Bluff California, a suburb of Houston (Alvin), and a suburb of Philadelphia.
- A member asked what sort of treatments, Vinblastine and etoposide were, and another asked whether anybody had been on them, but nobody had. These are drugs that are used as part of chemotherapy.
- We were reminded that the summaries of these Chats are forwarded to several doctors at Penn. A couple of them, do respond from time to time, so they do read them, and, hopefully, appreciate being in our loop.
- A member asked whether everyone had got their ECD surveys, and we were encouraged to complete them.
- Members discussed, their relative ages at diagnosis, and when symptoms had started. One had started to have health problems at 14, and another "as a teen".
- A member was sorting out airline tickets, as well as being on the chat. (Multitasking! It could only have been a female member!) She is thinking about another Florida trip, since her parents will be going there for 2 months.
- Some members compared their symptoms. One had pains in the knees and ankles, weight loss, stomach problems, and issues with cloudy bones. Another had looked at his MRI/bone scan CD, last night, and definitely, has cloudy bones. His symptoms had started in his calves (like he had just started running after having a few years off). A member had started with pain in the knee, and had had to have a reconstruction with metal and cement. She had played softball since the age of 8, and the Dr had said that she had thick bones due to that. It made it hard to do a bone marrow biopsy.

- A member had gone away from home, and forgotten to take his medicines with him! Mentioning medicines reminded another member that her, once weekly, Interferon shot was scheduled for tonight.
- Some members have had recent falls. One had had 2 falls yesterday indoors but, luckily, hadn't hit her head. She had been just walking from her office to her car. Then she went to the gym, and fell when she got inside that too! She now uses walking sticks, almost all the time, when she walks outside, but didn't have them when she fell, because she was only walking "a little way". On her recent visit to the NIH, she had been given some stretching exercises too, but nothing else. This member still drives.
- Another member who falls, said that it was as if he couldn't lift his feet off the floor.
- And, finally, on the subject of falls, we were told of another member who had fallen, a few days back. Leaning over, to pick up a laptop, had been the cause. The member has some bumps on her forehead but no injury. This member has been given a script for more physical therapy. If this doesn't help, it will at least give her more activity outside the house. She has "a terrific team of PT folks", and medical visits are rather pleasant events.
- A member, who has had a bad back, said that there is still some pain, but things were improving. Sitting in one position, for too long, is not good.