

Summary of ECD Global Alliance Internet Chat 18 May 2013

8 Attendees

- Simon&jo came on before the Chat started. They were going out for a meal. 19 May is their Wedding Anniversary (a poor excuse!!).
- A member who has not been on many Chats started things off. He was diagnosed in 2009. He was on interferon until June of last year, when he had AML (acute myeloid leukaemia) diagnosed.
- Another member, diagnosed in 2001, has been treated with interferon, and is now taking kineret.
- Another Chatterer had been on kineret for 2 years.
- A member is due to start chemotherapy with clofarabine in the next week. No-one else has any experience of that medication.
- There were 2 other Chatterers who were on interferon; one since 2007, and the other since 2005.
- Some members said that they would be going to the conference in San Diego, and that they, and their carers were looking forward to meeting other members and their carers. Some "sights to see" were recommended; The San Diego Zoo, beach, shopping, old town, and the Coronada.
- Our Australian member came on. It was 0500 in Australia!! He was congratulated for getting up so early!!
- A member had woken up very groggy. He wondered whether it could have been due to klonopin (clonazepam) tablet that he had not taken the night before. This is used to reduce leg spasms. He had been "kicking" his wife while asleep!
- A new Chatterer asked about the medications that other members take for pain. Two members have used fentanyl patches. One had found that paracetamol (acetaminophen or tylenol) was often sufficient.
- A member, whose wife had died from ECD, last year, told us that her friends had raised \$3800 for ECD research. They all did Ikebana (Japanese Flower Arranging), and organised a 'market day' to sell lots of flower containers, and his wife's made up the bulk of the stock. Her beautiful containers have gone to good homes.
- A member had to leave early today, because a film crew was present, making part of the documentary that is being prepared for the Global Alliance.

- A member told us that his wife was doing all the keyboard work as his hands aren't steady enough to type.
- One of the new members has a 21year old son who has had ECD diagnosed. He is using interferon. He has lost his appetite after prednisone was stopped. There is still some vomiting, and he is fatigued, and in pain.