

## Summary of ECD Global Alliance Internet Chat on 08 Mar 2014

10 Attendees

- Before we started somebody came on and asked whether any people from Holland or Belgium were present. They were asked to contact Kathy at [support@erdheim-chester.org](mailto:support@erdheim-chester.org) to learn more about the chat sessions, and to obtain information from the ECD Global Alliance.
- We were told that Joaquin, a chatter from Spain, passed away on February 20<sup>th</sup>, in hospital, due to complications of the flu. Our heartfelt sympathies are sent out to his wife.
- One member was having “problems” with a misbehaving keyboard. He was having to swap keyboards every few minutes. At least it kept him busy, and stopped him from monopolizing the chat! ☺ [Editor’s note: Simon, I hope your keyboard problems are soon resolved! Glad the keyboard was working well enough to complete this chat summary.]
- A member said that it was a holiday weekend in Australia. He thought that it might be Labour Day. Another member told us that he did “not know about that sort of stuff” now that he is retired! “What’s labour?” he asked!
- A member has been having extreme back pains, but started physical therapy last week, so hopefully they will get better. She has also been having fevers and had a sore throat. It was remarked on that quite a few of the drugs that are taken by ECD sufferers may reduce the efficacy of the immune system, leaving us more likely to get infections. Some of us have a “rule” that any friend or other person coming visiting should not come if they were at all sick. Some only go shopping at quiet times, when there are less people about.
- Members talked about the problem of swollen feet, ankles, and lower legs. One had found this to be a problem after starting Kineret. Another had noticed this when he was ill enough not to be able to move about much. And another member had started having this problem when he began Gleevec. He is off that medicine now, but is still troubled by the swelling. He has tried many of the so-called “remedies”, and is on diuretics too.

If you have this problem it maybe of help to put your feet up (they have to be higher than your ass, otherwise gravity can't help!) Stockings, that compress the feet and lower legs, can help too (like the ones that you wear when you are having surgery, or bed rest). In the UK these stockings are called TED stockings. Exercising the calves can also be helpful. For instance, using the small pedal machines while you are sitting down (or walking a LOT!).

- We were asked about any plans to go to Bethesda later this year for the ECD conference. It was pointed out that this is only 6 months away. Two of the members on the Chat would like to go, but will have difficulties with the traveling required. Another is making plans already. This member has been on vemrafenib, and is due for a 3 month check up starting in the week of March 17. She is anxious about her MRI results. She does a lot of exercising and PT now, almost too much! She is "so eager to get better!" She hadn't thought that she could get that feeling again.