

## Summary of ECD Global Alliance Internet Chat 26 Jan 2013

### 11 Attendees

- A member, who could not attend the Chat itself, came on and left a message that, a head of nursing, at the hospital being attended, had been in contact, and thanked the member for sending the Chat summaries.
- A member told us about his current experiences with chemotherapy. He has been in remission for some years, but has been having increasing pains, and the doctors think that the ECD may be "kicking off" again. The member had had 3 chemotherapy treatments so far. These are once a week, and will go on for 6 weeks. There are some side effects; depression, difficulty swallowing and constipation. He has also been prescribed morphine tablets, for the pain, which will explain some of the side-effects.
- Another member said that they were doing OK, and the doctors had said that the disease was stable. Balance is still a problem, and walking is difficult. This member is still working. There had been job changes to make things a bit easier, and it is now much more enjoyable.
- A member, who had not been on the Chat for a while, said that they were feeling fine. A member, who is regularly on the Chat, was asked after.
- A member had seen their neurologist recently, and is about to start 2CDA. The member asked about the doses that other members had had. No-one was able to give this information, but one member, from the same country, has had 2CDA as under-the-skin injections. This was given each day for 5 consecutive days, and then repeated after 3 weeks. This went on for 6 months.
- A member, who has recently been to the NIH, was asked about this. The NIH "was great", and is still keeping in contact with the member and her doctors, with results. There has also been a recurrent problem with strep throat infections. Four times so far this winter! The member has been found to be carrying the bacteria, so some antibiotics have been started that will, hopefully, sort things out. This member is still taking classes, but only taking 2 on Monday and Wednesday, and 1 on Saturday, with an online class. That means that it is more spaced out, and there are free days to go to doctor appointments. School has been ok about this. The

business law class has been interesting (especially because the teacher is a practicing lawyer).

- A member told us that they had been doing too many things, and they were having leg pain, and shaking of the hands. This member has relatives, who have also had problems with strep throats.
- About 5 new people have registered with the organization in the past month. One is from Korea, and the email that Kathy sends back to them keeps bouncing back. Kathy asked a more computer-wise member, to see whether a message of some sort could be put on Facebook.

Some people on facebook, who don't live in the USA were unsure whether they should register with the ECD Global Alliance (ECD-GA). A member who monitors the facebook page has directed everyone towards the ECD-GA.

A few people on facbook also thought that the ECD-GA was automatically notified about new cases, by doctors. They were told that they need to register with us, themselves. Because of privacy issues, doctors can't give the ECD-GA any information about a patient. Details of the NIH study, and how even transportation has been covered for most patients, have been posted. Many had assumed it was a US only thing, although it is actually open to any one, world wide.

- The GA is about to have a community open up on RareConnect. This is a social media-like website provided by NORD. NORD and its partners will be able to do translations for the organization, free of charge. It will also, presumably, be a bit safer for people to post personal information, because it is a site dedicated to rare disease patients, and their families.
- A member came on who has stopped interferon, and gone onto chemotherapy, and is feeling better. Also vemuranib is being used. That is a new treatment, and it looks like it works for those who have the B-RAF mutation. The member is going back to work 13 hrs a week (Best wishes from us all!).
- A member is starting "Mobility" this week. This involves learning orientation and travel skills, for blind people e.g. learning how to use the white cane and be safe.