

Summary of ECD Global Alliance chat held on Saturday 8th January 2011

12 Present

- The group was delighted to learn that Rich and Kit became engaged this Christmas. Warm congratulations and good wishes have been sent to the couple.
- Issues regarding teeth/jawbone were discussed during this chat. Several patients have experienced loss of teeth, crumbling teeth/jawbone. It is thought that there is a link between tooth loss and ECD.
- Several patients on the chat (or represented on the chat) had suffered from cold extremities. One patient comment that these areas were susceptible to infection due to decreased oxygen flow in these areas and recommended the advice given to diabetics (who also suffer from this problem) which is widely available on websites relating to diabetes. One patient mentioned they had an underactive thyroid and suffered from feeling cold throughout their body.
- A patient who has been hospitalized for treatment received their second dose of IV methotrexate recently. It is too early to tell whether there has been a significant improvement, but there did seem to be a slight increase in feeling in the right arm and leg. The next treatment is due in two weeks time.
- A question was asked about how many cases of ECD there have been/ how many there are currently. A figure often quoted is '300 cases since 1930'. However, it should be noted that this refers to the number of cases that have been recorded in the medical literature, as opposed to how many cases that have existed or do exist. It is not known how many cases there have been in total; at present the ECD Global Alliance has 81 cases represented, mostly from the US but including seven other countries. It is generally thought that ECD is underdiagnosed.
- Issues regarding vision and ECD were discussed. One patient suffers from diplopia (double vision) due to retro orbital masses. This patient also has impaired colour vision and needs good contrast in written material. Another patient has to wear a patch as their eyes don't function together. One patient has just had cataract surgery which has resulted in a significant improvement in vision from 20/400 to 20/40/
- One patient has been receiving kineret for three weeks on a trial basis. So far the patient is doing well.
- The next chat will be held on Saturday 15th January 2011.