Summary of ECD Global Alliance Internet Chat
16 Aug 2014

9 Attendees

- A member, who had not been able to come onto a Chat for a while, told us that he has "had a lot going on, and not all good". He has been on V (Vemurafenib), taking 4 tablets in the am and 3 in the evening, and has been tolerating it OK. He is due for a PET scan in October. He has noticed a weight gain of about 30lbs in the last two months, and now he has a frozen shoulder. He is going to have this "manipulated". He will be given an anesthetic, and then have the shoulder moved by the surgeon. He hopes that "nothing tears too badly". He still feels tired all the time. His balance has not gotten any worse. He has developed some small skin cancers (Basal Cell Carcinomas) that he is going to "have cut off". This is a recognized side effect of V. He has found out that the other person in Nevada with ECD is still alive, and he is trying to get in touch with him, again.

- A member said that he found having a hobby helpful. He does wood turning for a couple of hours, and then he has to rest or take a nap and then try again.

- A member said that things were "so tight" that he is unable to afford a hobby of any kind. He said that he is probably going to be homeless in about 6 months! Suggestions of help were offered. He is a single parent (with 2 boys aged 13 and 18), and doesn't have the support systems that many do. He realizes that many people play the system, so that when someone genuinely needs help, it isn't given. ECD doesn't get the exposure that other rare diseases are getting. "None of us are famous."

- A member suggested that he might be able to get some information off the Internet, to show how devastating this disease can be, or maybe get his doctor to write something out about this disease that would help his claim. The member said that the doctor "doesn't seem to want to get that involved". Another member had the same problem until the doctor got to see the report from the NIH.

- Other members told us of their current situations. Balance problems and exhaustion were the common symptoms.

- A member who lives near Toronto, has just had his first week of cladiribine chemotherapy. He thinks that he tolerated it OK. He starts again in 3 weeks (for another week). He was diagnosed at the age of 49, about a month ago, and had symptoms for 4 years. He was first diagnosed as a case of retroperitoneal fibrosis. He had a kidney transplant in February. Then, orbital tumors were found. He hopes that the chemo will shrink them, without the need for surgery. He thinks that this is causing his issues with balance.

- A member, who has been on V for a while now, told us that she is now working 50%, 3 days a week. She was congratulated. She has been having some problems with her balance and has had her V dosage increased. She had it reduced at the end of June. She is now on 1 & 2. She has tolerated this so far, but has only been on it for 3 days. She leaves soon for her 3 week rehabilitation stay. This is a 7-8 hour ride north from where she lives.