

## Summary of ECD Global Alliance chat held on Saturday 11<sup>th</sup> July 2009

### 8 Present

- One member had a PET scan this week and is due to receive the results in two weeks.
- One patient took Fosamax this week and has experienced unpleasant side effects including bone pain and 'flu like' symptoms. The purpose of the drug is to help with bone density loss which may be caused by steroids. The patient has read that others have experienced similar side effects but also some patients have been helped by taking the drug.
- One member's son has recently had chemotherapy: the patient is feeling good and hopes to return to work.
- A few members of the leadership group are due to meet this week to work on paperwork to make our organization 'official'. They also have plans to meet Dr. Arceci. The meeting will be in Bethesda at a Genetic Alliance symposium.
- One patient who is experiencing significant problems is finding it difficult to obtain an appointment with an 'ECD knowledgeable' doctor.
- One member has received an acknowledgement from the 'Mystery Diagnosis' TV team after they submitted their story. Some general information about the group has also been sent to the team.
- There was a discussion surrounding the issue of obtaining disability. It was suggested it was an area that the group could usefully look into. It would be good if someone who understood the system would act as a contact point.
- Would anyone like to submit an article for the next newsletter? These may be long or short and on (almost!) any subject. The editor would be very pleased to receive articles at [stanceforlance@hotmail.com](mailto:stanceforlance@hotmail.com)
- One member described how bone lesions and a tumour on the heart disappeared after chemotherapy treatment.
- One patient has been experimenting using different injection sites for interferon injections. They suspect that the injection site used may make a difference to how severe the 'flu like' symptoms are after taking the drug. The initial thought is that it may be best to use one injection site until the 'flu' symptoms start, and then change sites.
- Heart problems were discussed by several patients on the chat, including issues with endocarditis and pericarditis.
- The benefits of Skype were discussed, it was felt that this usually works best one-to-one or in small groups.