

## Summary of ECD Global Alliance chat held on Saturday 1<sup>st</sup> May 2010

8 Present:

- One patient who found it difficult to reduce their steroid dose has been off steroids for four weeks now. They are feeling better than they have for a long time. Another patient who is currently being tapered off steroids reported that they often feel peculiar and lacking in energy.
- One patient is going for a PET CT scan on Tuesday. These scans are performed on an annual basis (approximately). The patient is currently on methotrexate.
- A patient has recently received approval for treatment with the drug Enbrel/Etanercept, which will be administered in the form of injections twice a week. It is hoped that this treatment will lessen problems caused by pericarditis and reduce bone pain.
- One patient reported the good news that they have not had to take any pain medication for a month.
- One patient is in a great deal of pain both from arthritis and granulomas that press on the ribs and lungs. They also suffer from loss of voice.

The question for discussion this week was:

**‘How does your illness affect the degree of depression that you have? Are you honest when someone asks you how you are? Do you cover it up, seek help, push forward, get angry, end up in bed unable to complete tasks? Simply, do you want to participate in life during those times?’**

Responses were:

- One patient said that mostly they covered up how they felt by using the illness when they were depressed. They told people that they did not feel well because of the pain, rather than saying that they were depressed due to the constant pain.
- Several patients said they found their faith very helpful when they felt low.
- A caregiver said that their relative did suffer from depression, but did not like to admit it.
- One patient said that they rarely felt depressed but have found the last few months trying, when they were trying to reduce their dose of steroids,
- One patient said they have been on antidepressant medication for a long time. Whenever they try to stop it, they become depressed. It is thought that the changes in the brain are due to ECD causing an organic depression (brain chemicals are reduced).
- Another patient also said they take antidepressant medication.

- A member suggested that items could be sold on ebay or Craigs list as a way of raising money for the group. If anyone is interested, please email to the usual address.
- The announcement that the ECD Global Alliance is requesting grant application proposals is now on our website. In addition it appears on the NORD website. NORD has also included it on their enewsletter and the HAA will be doing the same. Hopefully some good proposals will be sent in.
- A question was asked regarding whether anyone suffered from allergies more than the average person. Two people on the chat did suffer from allergies.
- The next chat will be held on Saturday 8<sup>th</sup> May 2010 at 3pm EST.