

## Summary of ECD Global Alliance chat held on Saturday 6<sup>th</sup> March 2010

11 Present

- A new member was welcomed to the chat. Their relative was diagnosed in December 2008. For years they suffered symptoms without a diagnosis, these included abdominal pain and leg swelling. The patient has heart involvement.
- Several patients reported that they are having a difficult time at present, one patient was just out of hospital for the weekend and several patients have spent considerable periods of time in hospital lately.
- A question was asked regarding the dose of prednisolone that patients are taking. One patient is on 60mg/day, another on 25mg/day and this is being tapered at present. One patient had been on 40mg /day for four months and this has been tapered for the last five months; they are now taking 4mg/day. This patient described some of the difficulties in tapering the drug, the fatigue has reduced but the skin has become very thin and bleeds easily.

Two patients had been on low doses for a long time and said they would find it hard to manage without it. It was agreed that while for some patients prednisolone seems ineffective, for some it is indispensable.

- Several patients mentioned big swings in their physical well being and one patient attributed this to the tapering of steroids.
- A patient diagnosed in 1984 described their continuous struggle with the disease. They are having kidney problems and are on dialysis every 2<sup>nd</sup> day. They take interferon and baby aspirin.
- One patient who was hospitalized with chest problems for three weeks in January/February has now been home for two weeks. The chest problems have resolved but their neurological symptoms are worse, with poor balance and slurry speech.
- A patient who has pericarditis has been looking into research that indicates that Kineret (used to treat bone pain) may have a positive effect in treating pericarditis. The patient needs to be tapered of prednisolone before Kineret could be started.
- A patient described their experience of taking Gleevec. They took 400mg a day and for three months experienced a positive response, with side effects being managed by taking ibuprofen. After this period, there was no further improvement and the side effects increased, to the point where they were intolerable. The drug was stopped in December and the patient is at present stable. PET scans indicated an improvement and the patient noticed improved endurance and a reduction in abdominal pain.

Another patient had recently had a poor experience with Gleevec. Immediately after starting the drug they developed fevers and severe fatigue. They have been seriously ill in hospital in January and the Gleevec has been stopped; consideration is now being given as to future treatment.

- A patient currently having a new round of tests to check on the side effects of long term diabetes has been enrolled in a research study. The study is to look for ways to detect the effects of diabetes from changes in the blood characteristics. The hope is to reduce the need for scans by being able to obtain more information from the blood work.
- At least a couple of patients in the group take medication for thyroid problems.
- Some patients find swallowing thin liquids difficult and there is a tendency to choke. A few patients find adding a thickening powder to liquids eases this problem.
- A new initiative for the chat room will be started next week. A question will be posed to everyone so that we can share experiences, feelings and concerns about that subject. It is hoped that it will be a positive development for the weekly chats. Any feedback on this suggestion would be most welcome.
- The next chat will take place on Saturday 13<sup>th</sup> March at 3pm Eastern time.