

Summary of ECD Global Alliance chat held on Saturday 19th February 2011

13 Present

- A new member was welcomed to the chat. This patient has brain stem involvement and has recently started treatment on 2-cda. Several patients on the chat had completed a course of 2-cda in the past, of these, three had experienced a noticeable improvement. However, one of these patients said that six months after completion of the course there were signs that the disease was increasing its activity, and treatment with methotrexate was then started. Most patients seem to have a six month course of 2-cda, with one week's treatment per month, and then a three week 'gap' before the next cycle.
- One patient being treated with gleevec (dose of 400mg/day) has been on this treatment for just over a year. The drug causes a few minor problems with their stomach; they find taking the treatment at night helps. Another patient who had taken gleevec (dose also 400mg/day) reported that they had only been able to tolerate the treatment for four months due to side effects. They did say, however, that they felt significantly better after only two weeks on the drug.
- A patient who has been on kineret for two and a half months reported that it had helped a lot with their arthritis and had helped moderately with bone pain. There had been no resolution of the pericarditis. This patient is having difficulty in gaining funding to continue the treatment.
- A study was published on February 14th entitled ' Presence of Erdheim-Chester Disease and Langerhans Cell Histiocytosis in the Same Patient :A Report of Two Cases.'
- A patient receiving treatment with high dose IV methotrexate for a new brain lesion is doing well at present. The patient is due to be admitted for a fourth treatment shortly. Another patient with brain/chest/kidney involvement is doing well on treatment with lower dose methotrexate (40mg/week). A recent PET CT scan of this patient indicated that there was no active disease at present.
- The issue of fatigue was discussed, with several patients experiencing significant fatigue and sleepiness.
- The next chat will be held on Saturday 26th February at 3pm EST.