

Summary of ECD Global Alliance chat held on Saturday 9th April 2011

8 Present:

- One patient has been in ICU recently with kidney failure.
- Several patients on the chat commented that they thought that treatment with Gleevec had been extremely helpful. One patient had to stop treatment after three months due to stomach problems but still thought that overall they had benefited from the treatment
- A patient has recently been admitted to hospital for their 6th methotrexate treatment for a brain lesion. The patient is progressing slowly and steadily improving.
- One patient has been in remission since December 2009; their doctor has commented that all growths are now scar tissue and that the bone lesions have disappeared completely. This patient has previously been treated with prednisolone, cladribine, interferon and had radiotherapy for orbital tumours.
- The next chat will be held on Saturday 16th April at 3.00pm EST.