

## Summary of ECD Global Alliance chat held on Saturday 16<sup>th</sup> April 2011

7 Present:

- One patient is doing well on methotrexate (40mg taken once a week). Recent scans indicate no active disease at present.
- Another patient mentioned that they thought that interferon treatment was still working well for them.
- One patient has just returned home after six days of tests. The patient is currently taking Gleevec and doctors were considering treatment with Kineret but have decided to stay with the present treatment for now.
- Dr. Vaglio, who is conducting a study on ECD, has to date only received 5-6 records from patients. Members were encouraged to send records if at all possible. Details of the information needed and the address to which information should be sent are on the website.  
(see <http://www.erdheim-chester.org/VaglioPhenotypeStudy.html>)
- A question was asked regarding neuropathy in the feet and legs. Two patients on the chat suffered from this. One patient said that they thought this had been caused by an extended stay in ICU, rather than ECD itself. They said that that their feet often feel numb and always feel cold.
- The next chat will be held on Saturday 23<sup>rd</sup> April at 3.00pm EST.