

Summary of ECD Global Alliance chat held on Saturday 25th April 2009

10 Present

- A member who had not joined the chat before was welcomed. Their son was diagnosed five years ago and is now 38. He has taken interferon for some years and is still in remission. He has had lesions in the long bones and also eyes, although his eyes have improved now.
- A question was asked about whether anyone experiences numbing or tingling in the fingers. One other person had experienced this although this may have been due to an accident rather than related to ECD.
- Several members reported that they have started gathering copies of their medical records for Dr Vaglio's study (see e mail sent recently to all members for further details on how to participate). Dr. Vaglio is a research physician in Parma, Italy who wants to study the medical records of ECD patients to see if he can learn more about the disease. 14 people have currently agreed to participate, which is 6 short of our target. It is hoped more members will agree to participate. Once enough people sign up for the study, details will be sent regarding exactly what information is required for the study.
- One member will commence treatment on cladribine this week.
- Several members discussed their visual problems. One patient has had their optic nerve crushed by masses and has very limited sight. One member reported that their vision can change on a weekly basis. One patient reported a recent improvement in vision, which they think is due to taking interferon.
- There was a general discussion regarding possible environmental and dietary causes of ECD.
- One member stated, 'there was exuberance in the group' for this chat. A number of people expressed their positive feelings that the group and chats are available to offer support and friendship.