

Summary of ECD Global Alliance chat held on Saturday 6th February 2010

13 Present

- A new participant was welcomed to the chat; their spouse was diagnosed with ECD two years ago. Other members on the chat described when they had been diagnosed, one also two years ago, one fifteen years ago and one patient twenty two years ago.
- A question was asked about patients' experience of Gleevec. One patient had taken the drug for several months and had benefited from a substantial improvement which made a huge difference to how they felt. The drug had been discontinued due to some side effects, but the improvements that were experienced had been retained.
- A patient who has been on interferon for two years reported that their insurance company had decided that they would no longer pay for the drug, stating that ECD is no longer on their list of 'approved ailments.' Members encouraged the patient to continue to challenge this decision. Other patients on the chat had not experienced these problems.
- Members have received positive feedback from writing to governors regarding Rare Disease Day and there have been good results in getting US governors to sign the declaration for the day. The group will shortly be sending articles for submission to local newspapers and members are encouraged to consider doing this.
- Members commented that the weather can affect how they feel.
- One patient has experienced a significant reduction in bone pain since commencing the drug Kineret.
- One member has been involved in producing a video clip to promote awareness of ECD
- A question was raised about the link between interferon and depression. Patients do experience depression but this was felt to be due to the illness itself rather than related to a particular drug. Anti depressants are used by some patients with good effect.