

## Summary of ECD Global Alliance chat held on Saturday 13<sup>th</sup> February 2010

13 Present

- A new participant was welcomed to the chat; their relative has just been diagnosed with ECD and has bone involvement. They were encouraged to register with the group in order to obtain information and support.
- One patient has just returned from two weeks at an oasis of healing which they found a positive experience.
- A patient who has been suffering from morning sickness is improving now.
- A patient on cladribine reported that a scan after the 4<sup>th</sup> cycle indicated a possible slight improvement. They feel OK the week of the treatment itself but feel some effects a couple of weeks later. They have just had the 5<sup>th</sup> cycle of treatment and are expecting to have a 6<sup>th</sup> cycle.
- A patient who has been in hospital for the last three weeks with pneumonia is much better and was discharged on Tuesday this week.
- A patient who is currently on interferon and fairly stable has been informed that the doctor is considering stopping the interferon. The patient and his relative are concerned about this possibility. It was mentioned that all the physicians on the ECD website have indicated that they are happy to be contacted by other doctors to discuss individual cases.
- A patient who recently took Gleevec described how it had made a huge improvement in the lungs and in controlling abdominal pain. The drug had been stopped due to side effects; however, the patient was relatively stable and determined to celebrate the improvements!
- It was briefly discussed that the weather can affect how patients feel. Most patients feel best in moderate conditions.
- Several patients on the chat suffered from leg pain; it was mentioned that one patient has recently started taking the drug Kineret for bone pain with very good effect.
- One patient is in remission and has been off all drugs since August. The bone scans are clear and the MRI scan shows only scar tissue. This patient has taken prednisolone, cladribine and interferon.
- A patient described how they were having more problems with granulomas on their ribs and in the lungs. They take Imuran with no side effects but with no indication to date that it is having any good effect.

- There was a discussion about the differing density of lesions in different patients and different parts of the body; one member wondered whether this was related to the varying responses to treatments. One member described how, during surgery, the optic lesions were found to be very dense. It was agreed that the disease affects patients in very different ways and the response to treatments also varies widely.
- Several patients mentioned that they use Wii games for exercise!
- The next chat is scheduled for Saturday 20<sup>th</sup> February, 3pm Eastern time.