

## Summary of ECD Global Alliance chat held on Saturday 27<sup>th</sup> February 2010

12 Present

- A patient described how thankful they were to be able to talk to people on the chat room. If you have a rare disease it is difficult to get in touch with other patients, to know where to go for treatment and what the treatment options are. These difficulties are some which will hopefully be highlighted on Rare Disease Day, which is February 28<sup>th</sup>. The patient described how the chat room was a safe place to share information; you can keep your identity hidden or share it, whichever you wish. Another member pointed out that there were four countries represented in the chat room this week!
- Two patients have had a very difficult week. One has spent the week almost entirely in bed and has severe nerve problems in the lower back and also has infected teeth. Another has felt very sick each morning, is unable to sleep at night and has found that a new pain medication is not effective.
- One patient is still finding walking very beneficial. Walking is a little difficult sometimes when the leg pain is higher but the patient manages to walk most days.
- A member who has not been to the chats for a while described the medication regimen for their relative: interferon alpha 9m per week and vinblastin once in four weeks. Overall the patient is doing well.
- A member described how their relative is in remission and enjoying life. They have been off all ECD medications since August and have had no recurrence of ECD.
- A new TV show, 'Disease Detectives' from the National Institute of Health, is being shown on the Discovery Channel on Sunday nights at 8pm Eastern time, repeated at 12 midnight Eastern time. It looks to be a promising new show that may be helpful to members.
- A patient previously on Gleevec, which helped a lot until side effects started, reported that they are feeling good now.
- A patient has been having difficulties in getting interferon covered by their insurance company. Their doctor is trying one last attempt this week.
- A couple in the group have just returned from a wonderful time at the Winter Olympics with their grandson!