

Summary of ECD Global Alliance chat held on Saturday 21st November 2009

12 Present

- A message was posted prior to the chat suggesting a get together, possibly about a year from now. Any thoughts or ideas about this suggestion (eg. location, format) would be very welcome.
- There was a brief discussion on the limitations caused by fatigue. Patients find that they can't do too much in one day.
- A question was asked regarding whether patients who had taken cladribine had suffered from stomach upsets as a side effect of the drug. Three patients said that they had experienced this side effect.
- Members on the chat discussed how steroids can cause increased appetite and weight gain.
- One member asked whether taking steroids had helped with leg pain, one patient reported that steroids had initially been prescribed for leg pain but now oral pain killers were taken as needed to control pain.
- The role of exercise was discussed. One patient would like to exercise but finds that, if they do, they feel worse for quite a time afterwards. Another patient finds walking very valuable but has to be careful not to overdo it, otherwise problems with leg pain arise. A doctor had recommended water walking to one patient and this patient found that this helped their balance.
- A member who has been working hard on producing Christmas cards to be sold in aid of ECD Global Alliance has recently completed the art work for the cards. If you would like to view the cards please e-mail rjcmorgans@wildblue.net.
- One patient is taking Imuran to treat a growth behind the eye, so far with no ill effect.
- There was a discussion regarding obtaining disability. Amongst the members on the chat, there were a wide range of experiences. Several patients had waited for a considerable period before obtaining disability and had needed to complete a large amount of paperwork. One patient is currently engaged in a struggle to obtain benefit. Another had not experienced any problems in obtaining disability.
- Members wished each other a very happy and peaceful Thanksgiving!