

Summary of ECD Global Alliance chat held on Saturday 19th December 2009

13 Present:

- The Christmas cards designed by a member for the ECD Global Alliance have been widely praised and have received many compliments. Sincere thanks were expressed for all the hard work put into producing the cards.
- One ECD patient who acts as a carer for their seriously ill partner has been finding life very difficult recently. They wanted to share that ‘with prayer and determination and a little bit of Prozac, I found that Christmas Spirit that was sorely lacking in my life. This has been a big hurdle for me to climb.’
- Three other patients represented on the chat take anti-depressant medication.
- Question: does anyone suffer from skin problems? One other patient on the chat suffered from psoriasis on the scalp, and used Synalar gel and Capasal shampoo to treat it. (NB these are the English names).
- Question : do any patients take coumadin to reduce the risk of blood clots? Two patients on the chat took anti-coagulant medication. One patient had a pulmonary embolus two years ago, that was thought to be related to ECD, and has now been prescribed anti-coagulants indefinitely. Another patient had recently received test results that indicated an increased risk of clots.
- A patient had been experiencing problems with interferon, it had been recalled and was probably not as strong as it should have been.
- A patient who is taking cladribine is shortly due to have bone scans and a CT of abdomen/pelvis.
- A number of patients are currently suffering from leg pains. One patient who saw a rheumatologist recently has been prescribed Kineret, which can be given in one daily shot, to help ease pain, and will let the group know if these proves effective.
- Fentanyl patches were used by one patient (50mcg) for the treatment of pain and they found this worked well.
- A patient told the group that they take a small dose of steroids during the week of chemotherapy, which makes them feel better that week; they have more energy and less pain. Another patient also reported that they had had less pain while taking steroids, although the side effects had been bad.
- A patient described that they have wedge fractures in several thoracic vertebrae.
- For the next newsletter, the editor is considering including pictures of patients and carers. Please e-mail any pictures you have to stanceforlance@hotmail.com

- One carer described how a patient is doing very well at present and not taking any medications at all for ECD. This patient has hydrotherapy twice a week along with physical therapy.
- A suggestion was made to have a message board on which people could leave addresses. People could then get in contact with others if they wished.
- Two patients have suffered from pericardial effusions and required pericardial windows.
- Two patients experienced the onset of diabetes insipidus in the earlier stages of the disease.
- Members wished each other a very Happy Christmas!