

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

14 Present:

- A patient is due to start radiation therapy on April 7<sup>th</sup>, which will be for a minimum of four weeks. Another patient on the chat had received radiation therapy in the past (for 5 sessions).
- A patient is now on calcium supplements following a bone density test which showed a loss of bone density in the past year. This patient is also on Gleevec and so far is doing OK with it, with no noticeable side effects and a little more energy than previously.
- Everyone welcomed the recent news that the ECD Global Alliance has been granted tax exemption status! All fundraising ideas would be very welcome. Some ideas include Christmas cards, blank note cards, 50/50 raffle, label pins with the ECD logo. One member on the chat suggested that there be a memorial site on the web; so often when a loved one is lost relatives will request donations to a charity. Members on the chat thought this a very good idea.
- One patient has just finished their last (6<sup>th</sup>) round of cladribine and will have scans in four weeks time.
- One patient is suffering from pain in the eyes and headaches. They cannot read at present and are hoping to see an eye specialist shortly.
- In last weeks chat a new initiative was introduced i.e. to discuss a specific question each week. Feedback was requested on this; everyone thought it was a good idea and helped to give some focus to the chats.
- The question for discussion this week was ‘How does stress affect your pain level, ability to perform daily tasks? Does it depress you, cause lack of focus, make you tired? How do you handle it to get through the day?’

Responses were as follows:

- Patient 1 : ‘Yes’ to all questions, ‘I try to take one thing at a time’.
  - Patient 2: Pain levels are very high when stress is present, the patient sometimes finds it difficult to eat, becomes very depressed and questions why they have this illness.
  - Patient 3: The patient becomes upset very easily when under stress.
  - Patient 4: The stress does not affect pain levels but causes depression and irritability.
  - Patient 5: Stress increases pain level to point of being bed ridden. This patient also described the stress of being both an ECD patient and also a caregiver. This person’s faith helps them handle the stress of the situation.
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- The question for discussion next week is, ‘If you are a caregiver, how has this illness changed your life? If you are the one with the illness, what changes have you seen in your caregiver or other family members?’
  - The next chat will be held on Saturday 3<sup>rd</sup> April, 3pm Eastern time.