

## ECD Chat Summary 10 September 2011

### 7 Attendees

- One member came on before the chat to tell us that Saturdays will be taken up with soccer for a while.
- A member has just started interferon treatment, and feels well so far. Others who have already had interferon treatment discussed whether they had had, or not had, side-effects.

The member who has just started interferon said that she was taking 50 micrograms of Pegintron once a week. Others told us what dose of interferon that they had had, but the units were not the same, and so comparison is not possible. Also there is one type of interferon that is only given as a once weekly injection, while the other type is daily or alternate daily injections.

- A member, who has been seriously unwell in hospital, is making steady improvement. She has started a course of chemotherapy (Cladiribine) with steroid cover. Interferon had been used previously, with no bad side-effects, but no good effects either. Her spirits are holding up at this difficult time, and she has good relationships with the staff at the hospital. Her medical team are going to put her records together so that they can be used in one of the research studies.
- The doctors involved in the above case had heard of another Alliance member who takes 40mg methotrexate once a week. It was thought that this dose would be too small to cross the blood-brain barrier. The member taking the methotrexate did have active areas of pontine and cerebellar disease, a couple of years ago, and this is now quiescent according to recent scans. The details of the physician treating the member on methotrexate were given (Prof Pete Hillmen, Professor of Haematology, St James' University Hospital, Leeds,UK.)
- The recent article from Japan was mentioned. See - <http://search.japantimes.co.jp/cgi-bin/nn20110903a8.html>.
- A member who has been having pains in his shoulder and down into his arm, is about to have an MRI.

- A short discussion was had about sub-atomic particles. This began because one member thought that he had “quirks” in his computer. The Higgs Boson got a mention, but no-one had seen one of those flying around recently. Must be the wrong season!
- A member FTSOTP (relative to all you Americans) is going ahead with plans to visit NIH. Her Doctors are translating her notes from their own language into English! Advice was given concerning travelling distances, suitable shopping facilities, and other important matters. (Note: FTSOTP = From this side of the pond)
- After the Chat had finished a new member came on called bluesky\_opensea. She is the wife of a newly diagnosed patient, and is trying very hard to get any information about ECD. She has written that she will be back next week.