

# Summary of ECD Global Alliance Chat

## 3 September 2011

### 12 Attendees

- One member, whose husband is ill, signed on to say that she wouldn't make the chat, but then she did manage to attend for a short while. Her husband has had a catheter put into his abdominal space, and his team have removed 12 litres of fluid over the last few days. The histiocytes in the bone marrow have increased in number and he has started on chemotherapy.
- A member recounted the story of a patient, and asked all of us who are able to get involved in the NIH study. The patient's doctor believes it is important for as many patients as possible to join the study. In his opinion the NIH could lose the funding for the study if not enough patients are seen. Any questions about the NIH study ( or about other ECD studies) please contact Kathy at [support@erdheim-chester.org](mailto:support@erdheim-chester.org)
- A member said that her family member with ECD is going to the NIH on 1<sup>st</sup> October. Another member has just sent his consent form. Another member is due to speak to Dr Estrada-Veras of NIH soon to schedule a stay at the NIH facility. One of our European members is also trying to organize things for a trip to NIH!
- A member has been feeling rather stiff from working out at the gym (isn't that how you are supposed to feel? ☺). She has been told that the health system in her country will pay for interferon treatment.
- A patient has had to defer having physical therapy because she has a spinal compression fracture, and recovery is slow.
- Tropical Storm "Irene" managed to avoid the members who attended.
- Members were very pleased to receive the news concerning a member who has been extremely ill. Last week, she was not expected to survive. But she has made good progress and her family are very optimistic.
- A member has had botox injections in her her legs to try to reduce muscle spasms.
- Another is shortly due another MRI and then sees an oncologist, but there are problems regarding communication between insurance provider and the doctor.
- A member is going to have a neuropsychiatric evaluation due to some cognitive changes.
- The sea shore of Jersey has made for a good holiday for some.
- Another member is having to leave a much-loved home, because the stairs are not now manageable.
- Another member is having serious problems with social security disability. Her benefits were denied, and they have claimed that she has been able to work full-time since July of LAST year! They were advised that a lawyer was usually needed in these cases. Medically, things have been going well but she still has many symptoms that would make work impossible.
- A member joined the chat room after the chat to share information about a news article that might be of interest. The very short article, appearing in the Japanese press, reports that it is the first time an ECD patient received a lung transplant. See - <http://search.japantimes.co.jp/cgi-bin/nn20110903a8.html>.