

## Summary of ECD Global Alliance Chat on 27<sup>th</sup> August 2011

### 11 Attendees

- A member who had not been on a Chat for over a year attended. He said that that being tired all the time was a particular symptom of his.
- A member said that his wife, the ECD sufferer, is presently in hospital with a MRSA (Methicillin Resistant Staphylococcus aureus) infection. He asked whether others had had similar problems. His wife is being treated for MRSA that developed after a hip surgery.
- One member had had a number of chest infections, but no-one reported having had MRSA. It was said that the immune system can be “lowered” by both ECD itself, and by the treatments that are used to try and fight the ECD!
- It was reported that some more members had managed to send documentation onto those doctors involved in ECD research. Members were encouraged to get their records put onto CDs, for ease of shipping, and the making of further copies.
- The member who had not “Chatted” for a year or so, said that his doctor was exploring the possibility of a “Mast Cell Disease”.
- Another member had been having back problems resulting from a vertebral compression fracture due to thinning of the bones. She has had to lie on a heating pad and rely on painkilling medicines. She has talked about pain-killing injections, but not had one yet. Another member also reported having had spinal compression fractures, found on a scan for other things. This patient had not experienced much pain. Another member had a friend with back problems, who got pain relief from injections into her back.
- One member said that he had brain lesions and was considering radiation therapy or radiosurgery treatments (gammaknife and cyberknife etc.). Another patient had had a pituitary growth (diagnosed as a pituitary adenoma at first) that was treated with 5 shots of radiotherapy. This patients reported the treatment helped.
- A new member, who has ECD themselves joined the Chat. Introductions were made. The new member has been having interferon for 5 weeks. Another member on interferon discussed the problem of flu-like side-effects, and that it had taken a year of treatment before any improvement was noted in their case. A member cited confusion as a side-effect of interferon treatment.
- A member who has just been on vacation had found that her energy levels were OK.
- A member who has posted “his story” on Facebook is going to have it put on the Alliance website.
- Someone asked whether people had difficulty concentrating. Quite a few people on the chat said that they do have some difficulties. Making lists is one thing that people do to help remember things. Somebody else suggested CoQ10 supplements, and others recommended B vitamins. It was said that medicines to aid sleeping can cause problems with concentration.
- A member complained of a feeling of a “pulled muscle” with no explanation for it coming on. A member did say that he got such pains in his calves and feet. He has found that taking a bar of soap to bed with him helps!!