

## Summary of ECD Global Alliance chat held on Saturday 26<sup>th</sup> February 2011

12 Present:

- A new member was welcomed to the chat. This patient was diagnosed with ECD in 2001. They have been taking interferon since then, until last week, when they started treatment with kineret.
- A patient who has been treated with kineret for the last three months has received the news this week that the insurance company has refused funding for continuation of the treatment. The patient has been pleased with the results after taking kineret for the last three months. It seems unlikely that the pharmaceutical company will help as they made it clear at the outset that they would only provide the drug for three months. The patient has written to a major newspaper in the hope that they may publicize the case and maybe persuade the insurance company/pharmaceutical company to reverse their decision.
- One patient represented on the chat is having a particularly difficult year. The problems with swallowing are worsening, they are having difficulty sleeping and they have been suffering with urinary tract infections for much of the year.
- A patient receiving treatment with high dose methotrexate for a brain lesion was in hospital this week for the fourth treatment, which went well, although whether there has been an improvement is as yet unclear. The patient is now at home; tiredness is the most significant side effect.
- A patient's teenage daughter joined the chat. She often gives her parent (who has ECD) kineret injections. The daughter described how she would like to be put in touch with other teenagers/young adults who have a parent with ECD.
- Several members are planning to wear their ECD t-shirts on Rare Disease Day (February 28<sup>th</sup>). One member had talked to their local hospital about Rare Disease Day (the staff at the hospital had not heard of it before). One member's local paper posted about Rare Disease Day on their Facebook wall.
- The organization will be ordering more ECD t-shirts on March 6<sup>th</sup>. If you would like one/some, please send your order asap to- P.O. Box 775, DeRidder, LA 70634. . They are \$25 which also covers post and packing.
- The next chat will be held on March 5<sup>th</sup> 2011 at 3pm EST.