

## **ECD Global Alliance Internet Chat 24 September 2011**

[www.erdheim-chester.org](http://www.erdheim-chester.org)

### **11 Attendees**

- A new member from Italy entered the Chat Room, but there was nobody on-line at that time. Hopefully he will be back to try again.
- The study by Dr Vaglio in Italy was mentioned. This may be useful to the new member who arrived before we got started.
- A member has been using and enjoying membership of the YMCA. Swimming is a particular passion.
- Another member, who has recently been having problems with back pain said that the back was improving with just a few more physiotherapy sessions planned, but shortness of breath has become more of a problem.
- A member, who has not been Chatting for some time came on. Their present dialysis treatments are taking 4 ½ hours, a reduction from the length before.
- The new GA status that was recently sent to members was mentioned and approved of by members.
- A member has suddenly started being woken up by hip pain.
- A member, who has recently been very ill, is staying in a nursing home at the present, so the spouse can have a hip replacement operation.
- Another member told us that he had had pain in the hip, requiring a hip replacement, and that it was thought that prednisolone use had caused the damage.
- A member, who has had some chest problems in the past, is going on vacation to New Mexico. It will be 6000 feet higher than where they live. Some supplemental oxygen is being put in the luggage, and an oxygen meter is being taken so that a careful watch can be kept on blood oxygen levels !
- A member has been involved in giving an interview to try to increase awareness of ataxia (a general unco-ordination, one of the MANY symptoms that can be caused by ECD). It is for a weekly news magazine, sent to all Family Doctors in the UK.
- One member is doing well enough, for the endocrinologist involved to ask for DDAVP and Niaspan to be stopped.

- A member came on who has recently lost her spouse to ECD. She was welcomed to the Chat, and said that her family and friends are providing love and support.
- A member who had been using interferon for a long time reports doing well on Kineret. Only side effects may be a higher blood pressure, and the member feels a lot better than when taking the interferon. A nephrostomy had been necessary in the past. This makes infections more likely, so antibiotics are taken 3 times a week, and the nephrostomy tube is replaced every 2 months. A recent MRI scan showed that there was still some ureteric obstruction so the tube has been left in place.
- It was mentioned that the NIH study is large enough to cope with 100 patients.
- Some members had all been first found to have eye problems such as proptosis, or swellings in the eye sockets. This was before ECD was diagnosed. One member had found that these problems responded to interferon treatment.
- Another member had had a pituitary gland swelling and this had caused Diabetes Insipidus.
- It was discussed as to whether various symptoms that had appeared earlier in life, before ECD was diagnosed, were actually early signs of the disease.