

## **Summary of ECD Global Alliance chat held on Saturday 4<sup>th</sup> September 2010**

8 Present:

- Several members reported how much they appreciated the recent special edition of the newsletter.
- One patient who is in remission has now gone a full year without taking any medication specifically for ECD. Recent tests showed there was no sign of active disease.
- One patient reported that Intron has had the effect of shrinking a growth in the abdomen.
- A 45 year old patient is scheduled to have cataract surgery in the next two weeks.
- A caregiver described how unwell their relative is at present. ECD has caused the bone marrow to become sclerosed which is preventing the production of red blood cells. The patient will be discussing treatment options with their doctor shortly.
- The next chat will be held on Saturday 11<sup>th</sup> September at 3pm EST.