

## Summary of ECD Global Alliance Internet Chat 4<sup>th</sup> August 2012

### 11 Attendees

- A member came on early to say that they would be at a relative's graduation party. They left a query about whether anyone was getting cramps in the lower legs, and reported that melatonin was helpful if you are having difficulty sleeping.
- Another member came on early to say that a relative had had blockage of the renal arteries, due to retroperitoneal fibrosis from the ECD. A urologist was consulted about this condition.
- Another member has seen a surgeon about kidney issues, and is very optimistic that both kidneys can be saved. A rheumatologist is going to be consulted about treatments as well.
- We had been told last week that Norway closed down for the holidays! Our member, from Scandinavia, said that people have between 4 and 5 weeks holiday in July/August (including the doctors!), so things sort of "stop".
- A member was welcomed on who had recently moved, and had no internet yet.
- We were asked whether any of us had "good and bad days" or problems with fevers. A few members said that they do have differing days. One member said that her partner used to be troubled with night sweats and temperature spikes.
- We were reminded that it is very helpful if we make sure that we notify the Global Alliance of any change of address, or change of e-mail address. ([support@erdheim-chester.org](mailto:support@erdheim-chester.org))
- A member told us that a first grandchild had been born safely. Other members offered congratulations.
- A member has a date to go to Maryland (30 September 2012), and is excited by the prospect. A member, who has already been to NIH, told us that Dr. Estrada-Vera has said that he would like to review patients, but not until a year had passed since their first visit.
- A comment was passed about the numbers of us who were still working. One member is still managing full-time work, despite feeling tired, but no others said that they were still working.
- A member had recently had botox injections to try to reduce spasm and stiffness in the legs. Unfortunately this has not helped. Sometimes the legs feel like they weigh 50lbs!
- An enquiry was made about how long members had had the diagnosis of ECD. Kathy said that she had talked to patients who been diagnosed more than 20 years before.

- A member who has recently started on interferon, said that there was a slight improvement, but that a swollen lymph node in the right underarm region (axilla) hadn't gone back to normal. Another reminded us that regular blood work was needed to keep an eye on things. One member's liver had not been a "happy camper" when interferon had been used.
- A member had "overdone it" working in a hot yard. This had caused wobbliness and dizziness.
- It was agreed that very few people understand what ECD patients have to go through. One member had been told "You Don't Look Sick". There is a US website, called [www.ButYouDontLookSick.com](http://www.ButYouDontLookSick.com), that is concerned with illnesses rather like ECD. This site might be helpful to members.
- A member came on after the chat and has a scheduled visit to the NIH on Dec 17<sup>th</sup>. Today's chat had been "forgotten", but the member had managed to get ear piercing done!