

Summary of 2-1-09 ECD Chat

Chat Date:

2/1/09

Time:

3:00 pm Eastern time

7 Attendees

Summary:

- Time was spent by the participants just chatting about what is happening in their lives.
- Information was passed onto one participant concerning contact information about a doctor who lives in Australia.
- There was a brief discussion about the HAA Message Board. One of our participants has been doing a good job of reviewing the board on a regular basis and responding to those who post there searching for information and/or contact. Thank you!
- The hospital one where one of our members works in has just published an article about Feb. 28th being Rare Disease Day.
- At least one patient indicated she seems to be feeling better and attributes it to eating better and getting more rest and sleep.
- There were thanks given to those who published the first ECD Global Alliance Newsletter recently. People found it informative and easy to read. At least one person sent it on to her family and friends who have a hard time understanding what it means to have to deal with ECD. Everyone was asked to contact the newsletter editor at stanceforlance@hotmail.com with any articles or ideas for the newsletter. It was suggested that perhaps including recipes or other health tips in the newsletter might be helpful and interesting.
- One member of our group mentioned that he had passed some information about ECD and rare diseases onto his family this past Christmas. Recently when he talked to his aunt she mentioned that she had passed the information onto an ill friend. It is great to know that we can help others (and thus ourselves) when we continue to do all we can to raise awareness of rare diseases.
- Two of our patients have plans to see one of the physicians who have seen multiple cases of ECD. One will see Dr. Arceci in Maryland for the first time in the not too distant future. The other will see Dr. Haroche in

Paris in March. We hope they will have good appointments with these knowledgeable physicians and we look forward to hearing what they learn.

- A quick discussion was held about C-Reactive Protein (CRP). We learned that CRP is a marker of inflammation and can rise as the result of an infection or other inflammation throughout the body. Although CRP is an indicator of something going on, it does not help the doctors pinpoint where the problem might be occurring. A follow on question was asked about how the Sed rate (eg, erythrocyte sedimentation rate or ESR) differs from the CRP. This is also a marker for inflammation within the body, but it does not rise as quickly as the CRP.