

# Scheduled Online Chat Room Summary

**Date:**

5/28/08

**Time:**

4pm Eastern time

## 9 Attendees

### Summary of 5-28-08 ECD Chat:

- It appeared from the chat room activity between chats that some new people were interested in joining us, but for whatever reason were unable to do so. Anyone can email [support@erdheim-chester.org](mailto:support@erdheim-chester.org) if you have any questions or cannot make any of the scheduled times.
- During the chat it was mentioned that the HAA has written an article on ECD and it should be added to the website soon. The HAA will email the chat room participants an early draft copy for comments. A brochure will also be created, based on the information in the article.

Information about other activity the HAA has been up to lately has been mailed out. A lot of good information was shared via an email prior to the chat. (Please see below in the HAA News and Questions Corner.)

- A lively discussion was had about placing an electronic form of the ECD Patient Notebook information on the web. The idea of making this information available on the HAA website was talked about. The benefit of doing this would be to have a single site where people could go for all their up-to-date information. A couple ideas for doing this were shared. The first is the chat group (now known as The ECD Advocacy Group) would give information to the HAA and they would post it under the ECD Disease Information part of their website. Another alternative would be to create a link to a web site where the chat group could update directly.

We need to figure out what is the best method for making information available to those who need it with the least amount of trouble and cost. It was decided to give everyone some time to think about all the options and we would pick up this discussion at a later date.

- A mention was made that the HAA encourages US citizens to contact their Congressmen to let them know how important it is to them to have funding for research in ECD and other rare diseases.

## HAA News and Questions Corner –

- The HAA has a copy of the ECD directory form The Advocacy Group (that is us in the chat room) devised. They will work on getting this form ready for distribution and creating the directory for all ECD patients.
- The HAA is now giving out this chat room as a resource for patients who call in for information on ECD.
- There was a question about whether we wanted to work on a 'Rare Disease Notebook' rather than an "ECD Notebook'. We can discuss this at the next session. Perhaps we would want to focus on the ECD notebook and see where it takes us first?
- The HAA is requesting information from a few physicians about the 3 medications used in an HAA message board post on 4/14/08 titled 'Remission'. When the doctors respond, HAA will share the information.
- Our question regarding the relationship between NORD and the HAA will be addressed by the HAA. We do know HAA is a member of NORD.