

Summary of 6-20-08 ECD Chats

Last Chat Date:

6/20/08

Time:

3:30pm Eastern time AND
8 pm Eastern time

5 Attendees:

The session this week was again focused on sharing of information among participants without a specified agenda. The participants all indicated they enjoyed this 'free' format, although an agenda published before hand is nice when there are things that need to be discussed or accomplished.

Various treatments and people's doctors were discussed in a little more detail. People's experiences with ECD were also discussed.

The HA in the UK is doing an article in their next newsletter about ECD. Two of our participants have been asked to submit something for the newsletter.

Two of our participants have discovered they share the same doctor.

A recap of the group's 'projects' was discussed as follows:

Support. The idea of the chat room began as a way to provide support to each other; to reach out and let people know there are others who are also affected by this disease. Through this support sharing of information can occur and hopefully help everyone.

Patient Notebook. A notebook is being developed; first as a physical notebook to help new patients keep personal copies of their medical records organized. It was discussed that asking for CDs of ALL scans is a real help to doctors and saves time in the long run. The notebook will also contain information specific to ECD. Eventually the notebook material will be available on the internet, hopefully via a link from the HAA website.

Raising awareness of ECD. We are still 'brainstorming' ideas on how to do this effectively. We know the HAA is planning to attend the ASH (American Society of Hematologists) Convention this year and will be handing out flyers on the adult histiocytic diseases. Lots of work needs to be done in this area. We have thought about mailing out information to doctors, but the difficult part is getting them to read the information. The best way might be if more articles were published by the 'ECD knowledgeable' doctors in the recognized medical journals. The question is if we can help encourage this, and if so, how?

Increasing the knowledge of ECD. We are trying to get one or more of the 'ECD knowledgeable' doctors to join in our chat room. We have contacted a couple of doctors and have received back an email from one and an aborted phone call (another highly important call came in) from another. Unfortunately, we have heard nothing more. We continue trying and will be sending an email to a third doctor who has published multiple papers on ECD.