

Scheduled Online Chat Room Summary

Date:
4/30/08

Time:
10 am Eastern time

7 Attendees

Summary of 4-30-08 Chat:

- Reviewed case history of two new participants in the chat room.
- Discussed content of the ECD directory. Plan is to have a set of questions ready and mailed out to everyone by the end of next week (5/9/08) for comments. All the information will be sent to HAA for them to create a booklet and send it out to everyone.
- Requested HAA to invite ECD knowledgeable doctors to join in on our chats. The HAA is making the doctors aware and are telling them we would be honored to have them join us. We all hope one day someone will join us.
- Discussed theory that ECD is the result of damage to the body and until that is repaired we are only treating symptoms of the disease. Neural research could hold an answer to how to get things working correctly again. The HAA is strongly encouraging anyone doing research in this, or any area that shows a promise to helping in the fight against ECD, to apply for grant money.
- A request was made of the HAA to arrange a meeting of all the known 'ECD doctors' at the next ASH conference to brainstorm and get to know each other. The HAA will look into the possibility of this and will get back to us at the next chat session. The HS will meet in Berlin in October where ECD will be discussed.