

Scheduled Online Chat Room Summary

Last Chat Date:

6/6/08

Time:

3:30pm Eastern time AND
8 pm Eastern time

11 Attendees

Summary of 6-6-08 ECD Chat:

- Feedback to HAA on ECD Paper. The paper was discussed and comments collected to send back to the HAA. In general everyone was very appreciative that a paper was written. However, folks wanted to make sure up-to-date information was included. Things that were discussed that might be added were (1) newer testing protocols (eg, PET scans); (2) an update on the standard treatments (eg, interferon) being used and maybe some of the other treatments currently being given (eg, tamoxifen, Remicai/Methotrexate/Cellcept); (3) and the current results being seen with the newer treatments and testing protocols. The group is very appreciative that we were given an advanced look at the paper.
- HAA ECD Networking Directory. The group agreed that the addition of two optional fields for phone number and state were okay as long as it was very obvious that these fields are optional and are not required to be part of the directory. Once again there was discussion that the group wanted their information to be provided only to those who were members of the directory.
- Chat Room Agendas and Participation. Discussion was held about having our future chat sessions focus more on sharing of information regarding treatments, results, support, etc. We can rely on email more for some of the administrative stuff we have been discussing lately. All sessions will remain open to anyone affected by ECD who would like to participate. If a specific person (such as someone from the HAA) is wanted for a specific topic, a special invitation will be extended to let that person know their participation would be appreciated. We want all to join in on all the chat sessions, it is just understandable that this is not practical all the time.
- Name / Letterhead /etc. It was felt the letterhead done by YankeesFan was great. Thanks! There was some discussion as to whether the name for our group was appropriate. Ideas were discussed and it was finally decided to gather the different proposals for a group name and gain consensus via email. Ron did a great writeup on our initial objectives. This will be included in the Patient Notebook.
- Clarification on the group's purpose. A discussion was held to try to get clarification on the purpose and scope of the group. There are different thoughts and a real attempt is being made to try to get us all on the same page. In the meantime everyone seems to agree that sharing of personal information is one way that patients are being helped and can continue to be helped.
- Sharing of treatment and doctor information. The difficulty of finding ECD knowledgeable doctors and encouraging communication among the doctors was discussed. Sharing of information among patients seems to help the patients help the doctors communicate. Plans are to update the generic patient spreadsheet with information regarding symptoms/treatments for our newest participants. This will be available to all chat room participants when completed.