

Scheduled Online Chat Room Summary

Date:

5/24/08

Time:

3:30 pm Eastern time

6 Attendees

Summary of 5-24-08 ECD Chat:

- **Group Name.** A discussion was held about what to call our online chat group. Although everyone was going to think about it, a tentative title was chosen as 'ECD Advocacy Group' with a subtitle of 'A Group of Patients and Caregivers'. This may be tweaked as people have time to think about it. Some alternative definitions to ECD were also discussed, including 'Ever Cheerful Delinquents' or 'Earth's Cheerful Delinquents'. Work will be done to develop a letterhead to put on documents we produce as a group.
- **Letter to doctors from our group.** We discussed sending a letter out to doctors who are known to be interested in ECD or something similar. The letter would introduce our group, state our purpose, ask if they would be interested in working with us and just generally open the door for communication. The letter would initially be targeted to research physicians at the major teaching hospitals in the world (e.g. Mayo, Johns Hopkins, M.D. Anderson in the US and others elsewhere). We could include our generic patient information we have compiled. The feeling was this may or may not produce any action, but it can't hurt to try.
- **ECD Patient Notebook.** One patient and his wife have been busy and produced some good starting material for our notebook. Thank YOU! The rest of us seem to have had an unusually busy week and didn't get much accomplished. We all hope to change that this coming week.

A discussion was held about what website would be used for the notebook information. Although the intent is to produce a physical notebook to send to people who contact us or the HAA, we also want data to be on a website and available electronically. This will allow everyone to access the information and make it easier to keep up to date. We hope to get an answer this week from the HAA about whether they can give us access to some pages on their website where we can do updates. The information we produce will have to be written appropriately for our target audience.

HAA Questions (highlighted questions are from chat two sessions ago, other from last chat) –

1. Can we use have access to a page on the HAA website to host the ECD Patient Notebook information? If so, can it be set up so we can do updates directly?
2. Could the HAA solicit comments from some of the "ECD Knowledgeable' physicians about the proposed treatment of Remicaid, Methotrexate, and Cellcept as discussed on the histio.org message board under the topic of "Remission" on 4/14/08? The chat group is interested in hearing opinions about this treatment.
3. Can someone explain to us the relationship between NORD and HAA? In what way do these two organizations work together?
4. Does the HAA have any information about the ECD study done by the NIH back in 2002 - 2004? We are aware that a study was done, but no one has seen any information that this study produced. (We have discovered that Dr. Robert Shambureck, et. al., produced two publications from this study, but then the study was stopped.) Does the HAA have Dr. Shambureck on their distribution list to get HAA announcements regarding grants?