

Scheduled Online Chat Room Summary

Date:

5/17/08

Time:

noon Eastern time

5 Attendees

Summary of 5-17-08 ECD Chat:

- One patient shared some of the latest conversation he had with his primary physician. He will write up some of the things that he has found to be true in his journey.
- The ECD Registry form has been sent to the HAA. The HAA is working on it and hope to be sending it out to registered ECD patients shortly. We hope to see something soon from this effort.
- People's various experiences with using cladribine (2 CdA) were discussed briefly.
- A short discussion was had regarding cholesterol levels and how that could possibly be related to ECD.
- The ECD Patient Notebook was discussed. The notebook will be mailed out to new patients who call the HAA. It will contain dividers to help new patients keep their records straight. It will also contain information to help new patients understand what we know about the disease. For those patients with internet access, some of the information will be made available online in easy to download formats. This will help us keep the data current. We must work to keep the notebook simple, we do not want to overwhelm patients. It may be most important to provide a way for new patients to contact others as person-to-person contact may be one of the most helpful things we can offer a newly diagnosed patient.

People volunteered to help with certain sections of the notebook.

Anyone with ideas about any of these topics, or other topics that should be included in the notebook, are asked to respond with their thoughts and ideas.

- One patient touched on his method of pain control through brain wave technology.
- It was noted that the chat room is always open. If anyone is interested in having a chat in the chat room, they are free to do so at anytime. All you need to do is to find a time when others can join you.

HAA Questions (highlighted questions are 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?