

Scheduled Online Chat Room Summary

Date:

4/10/08

Time:

11 am Eastern time

9 Attendees

Overview: Discussed what we could do to build a better support/communication network.

Summary of 4-10-08 Chat:

Ideas about improving the support and communication around ECD were brainstormed. An attempt was made to organize the ideas by goal as listed below. Under each goal are:

- ideas, or things we can do
- discussion entries, or comments that were made which help define the ideas.

Goal #1: Improve communication among patients.

Ideas:

1. It would help if we had a central repository of email addresses for those affected by ECD.
2. Continue on with the chat sessions.
3. Try to increase chat room participation through information from HAA message boards.
4. Get everyone's diagnosis story and compile into a report or article.
5. Increase activity in HAA ECD message board. (We all need to work on this one. It is on the agenda for next chat session.)
6. Produce a general, generic data base of all the pertinent information on each 'case', not to include any personal data.
 - a. Make a separate list of known doctors treating ECD without tying the cases and doctors together.
 - b. Need policies in place to keep it up to date and decide how and where to share it.
 - c. Perhaps we could contact other patients registered with the HAA to see if they would mind participating.
 - d. This can be a simple spreadsheet with sex, age, treatment, symptoms, etc.

- e. This information will be redundant with the information being gathered in the registry, but since the patients don't have access to that information it may be necessary for now.

Discussion:

1. It helps to understand current medications, treatments and results.
2. If we stay in touch we stay current with the information, unlike articles written years ago.
3. We could set up an 'ECD Forum' as a lobby type group.
4. Most ECD patients will end up at the HAA by default today.
5. There is a greater need than the current HAA message board. That is why this chat room was started.
6. An ECD forum would be focused solely on ECD.
7. We could focus on trying to make the HAA ECD message board more active.
8. We could come up with specific questions to post on the message board in an attempt to get more information sharing on the HAA.
9. Sharing on the HAA board is perceived by some as risky as all the information can be read by anyone, although you must register to post.
10. Blogs are preferable to some because you don't have to retype the info and a complete patient history can be made available.
11. Whatever is done, no more user ids or passwords are wanted.
12. There may not be much sharing because it is such a rare disease.
13. Quit worrying about privacy issues, we've got a serious problem here. Let's do what is necessary to help. Yet, we must worry about legal issues and listen to people's concerns and respect their wishes or no one will participate.

Goal #2: Improve communication among physicians.

Ideas:

1. Send all known doctors treating ECD a letter with names of the other doctors who have treated ECD and beg them to consult with each other.
2. We could personally ask our doctors to share their experiences with ECD with other doctors and the HAA.
3. Get those doctors who wrote articles on ECD 7, 5, or 3 years ago to update them.

Discussion:

1. We need to help physicians understand the value of consulting with others when dealing with such a rare disease.
2. Doctors need to share their information regarding treatment and results in battling ECD. Early intervention may be life saving.
3. Are there doctors who have really treated 20 ECD patients? If so, what are their long term findings regarding treatments.
4. We could just give information to each other and then we could take that to the doctors rather than trying to get them to communicate with each other and the registry.

Goal #3: Improve communication between patient and physicians.

Ideas:

1. Ask Kurzrock, Arceci and others to post summaries of their perspectives on ECD.
2. We could provide doctors with the information gathered from this online chat group.

Goal #4: Improve participation in the HAA's ECD registry.

Ideas:

1. Simplify the ECD questionnaire.
2. We can 'bug' our doctors and nurses to get the questionnaire completed and sent in.
 - a. Let them know how important it is to you.
 - b. We can help each other to get as much completed ourselves before asking the doctors to do their part.
 - c. Keep calling the doctors to check on their progress.
 - d. Give the doctors one page at a time to complete.
 - e. Ask the doctors some of the questions while you are sitting in the office with them. Write them down and ask some more next time.
3. Divide the form into sections – one for the doctor and another for the patients (not that it has to be completed that way, just as a guideline.)
4. Ask the most important questions first, then if people don't have time to complete all the questions we'll at least get some information.

Discussion:

1. The questionnaire form is too long and difficult for most patients. Doctors are not always willing nor do they always have the time to fill it out. The danger is, in an attempt to collect all the information we may end up collecting none.
2. Of the 25 HAA registered ECD patients, only 8 questionnaires have been completed and returned. (Statistics obtained after the chat.)

- a. It would help if there was information explaining why these particular questions were being asked. How the information is to be used, etc. That would give people an understanding of what information is most desired.

Goal #5: Improve communication between HAA and patients.

Ideas:

1. Send letter out to registered HAA doctors asking them to refer ECD patients to the HAA web site.
2. Look into having the ECD message board set up to require registration prior to reading posts.

Discussion:

1. Patients need access to the current information about ECD from around the world.

Goal #6: Improve communication between HAA and doctors.

Ideas:

1. Send a letter to the doctors treating ECD to enlist their help.
2. Contact the British HA to get contact information about possible other patients in the UK. We have email contact already. Can we contact other entities in other countries? Perhaps other patients could help.
3. Patients need to ask their doctors to register with the HAA, otherwise the HAA does not know who is treating ECD.

Discussion:

1. Patients and doctors need to know the HAA exists and what support is provided.
2. Doctors need access to most current information about ECD from around the world
3. We need to get doctors to sign up with the HAA so all their information will be in the HAA database.

Goal #7: Improve knowledge of ECD in the general population.

Ideas:

1. Write an ECD article to get published in a major magazine / publication.
2. Create an ECD presentation.
3. Get the NORD database information updated.

Goal #8: Improve physician's awareness of ECD.

Ideas:

1. We could give the new ECD brochure being developed by the HAA out to our local doctors.

Discussion:

1. Need to educate doctors on ECD, most don't know it exists because it is exceedingly rare.

Questions of HAA. The HAA is working to get us answers to these questions.

1. Do we know if the 'ECD expert' doctors (eg, Arceci, Kurzrock, Jaffe) ever get together to share their data?
2. Can HAA help us get a list of doctors known to treat ECD along with contact information?
3. Could HAA help get a letter out to the above list that asked these doctors to consult with each other?
4. What information can the doctors get from the ECD registry? Can they get information today?
5. What information can the patients get from the ECD registry? Would it be possible for patients to get 'generic' information from the registry?
6. Can an analysis be run today on that ECD registry information that currently exists? Something is better than nothing. It could be updated as new data became available.
7. Will patients have access to the new online database/registry being established by the Histiocyte Society?
8. Can the HAA contact the doctors directly asking them to complete the ECD questionnaire? We've got folks who are willing to do this as volunteers on the HAA's behalf if the information can be made available.
9. Is the HAA still understaffed? We've got many volunteers who would like to help the HAA. Please tell us how we can do that?
10. Is it possible for the HAA to register in other states as some people and entities are more comfortable donating locally?
11. How can people be ensured their donations are going towards the fight against ECD? (Donations can be made as a grant designated to a specific ECD project.)
12. Is it possible to specify money raised during a fundraiser goes specifically toward ECD efforts?

What is HAA doing currently?

1. Establishing the ECD registry with data from ECD patients and their doctors. Once data is collected from the ECD registry it is shared with any physician wanting information.
2. Advertising on Google so that when ECD is searched, HAA appears.
3. New online database/registry is being established by the Histiocyte Society (this is the doctor's organization). It will collect data for ECD and other disorders. It should be up and running by the start of next year.
4. Letters have been sent to all known doctors treating ECD patients encouraging them to fill out the registry questionnaire.

5. An informational brochure is being written about ECD that will be suitable for both physicians and patients. It will be sent out by email to the HAA physician database and made available at physician meetings. It will also be sent out to all the ECD patients registered with the HAA.
6. Developing chat rooms for each of the HAA diseases.