

# Scheduled Online Chat Room Summary

**Date:**

5/10/08

**Time:**

noon Eastern time

## 7 Attendees

### Summary of 5-10-08 ECD Chat:

- The National Family Caregivers Association is a great resource for caregivers. Their website can be found at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org).
- The HAA is working on an article about ECD that they hope to have approved by the HS and posted on the histio.org website by the end of May!
- The idea of doing a 'point study' with a few ECD patients was discussed. 'Point studies' can be done with few patients and used to determine if a larger study is appropriate. Perhaps we could do something to see if we can determine why the immune system of an ECD patient acts as if there is an infection. To do this a specific question would need to be asked and the study designed to answer that question. The study would need funding and appropriately credentialed personnel to lead the study. We need to be proactive in finding the cause and cure of this disease. One patient agreed to take into consideration all that was discussed and come back to the group with a proposal.
- None of us have seen the results of the ECD study done at the NIH in 2002-2004. It was agreed that one of our patients would ask his Mayo doctor if he had a copy or was aware of whether the results were ever documented.
- A question was raised about the relationship between NORD (National Organization for Rare Disorders, [www.rarediseases.org](http://www.rarediseases.org)) and HAA. A request will be made to HAA asking them to give us input on this subject.
- The proposed form for the ECD directory was discussed. Everyone agreed that the team that worked on this had done a great job. It will be sent to the HAA with a request for them to gather patient information and publish a directory as quickly as possible. This is a positive step in that it will allow for much better networking among patients and their loved ones.
- The idea of creating a notebook for new ECD patients was discussed. This notebook might include forms and dividers to help keep medical information organized, tips for patients and caregivers, medical issues to watch for, list of questions that might be appropriate to ask doctors, ideas for independent living aids, etc. It would be a resource to help navigate the medical system. A beginning point will be pulled together and emailed out to participants. Anyone interested in working on a section, please respond to the email with what you would be interested in doing.

- The treatment of Remicaid, Methotrexate, and Cellcept as discussed on the histio.org message board under the topic of “Remission” on 4/14/08 was talked about. **A request was made for patients to discuss this treatment with their doctors and bring their thoughts back to the chat group.** A request will be made to the HAA to see if they can solicit any other doctors for their opinions.
- A small discussion on the side effects of interferon as experienced by one patient was discussed. This includes extreme tiredness, no energy and lots of naps. However, the drug provigil seems to help. For this patient the interferon has stopped progression of existing sites and no new sites have been seen since beginning with the interferon. Another patient said they got used to the side effects eventually and they were not too bad. A third patient gets relief through the use of acupuncture and shiatsu. Some resources for these treatments were provided after the chat as below:

### **Acupuncture**

<http://en.wikipedia.org/wiki/Acupuncture>

<http://www.acupuncture.com/>

<http://nccam.nih.gov/health/acupuncture/>

### **Shiatsu :**

[http://www.rianvisser.nl/shiatsu/e\\_watis.htm](http://www.rianvisser.nl/shiatsu/e_watis.htm)

<http://en.wikipedia.org/wiki/Shiatsu>

- A final discussion was had about how important it is for the ECD patients and caregivers to piece together the ECD picture. Together we have to figure out how to be effective and push the doctors in the right direction to get results.