

## Summary of 6-27-08 ECD Chats

**Last Chat Date:**

6/27/08

**Time:**

3:30pm Eastern time AND  
8 pm Eastern time

### 7 Attendees

The majority of each session this week focused on getting to know each other better and sharing of personal histories without a specified agenda.

A short discussion was held in both sessions regarding the ECD Registry Questionnaire that is needed for the HAA ECD project. Currently 8 questionnaires have been completed and returned. The following were comments given as to why it is so difficult for patients and their doctors to get this form completed and returned to the HAA:

- Form is too detailed; form is too long
- Patients tire easily
- Doctors are too busy
- Don't understand the appropriateness of some of the questions (eg, income level)

Some possible suggestions to remedy some of these issues were brainstormed as:

- Rather than ask for all the information to be filled out on the forms, ask for specific reports and such and have someone else extract the needed data
- Simplify the form

The next chat is as of yet unscheduled. This Friday, is Independence Day (July 4<sup>th</sup>) in the US. Will get message out later in the week as to whether the chat will be held on Friday, rescheduled for another day, or we will just wait until the following week.