

# Draft ECD Online Chat Summary

**Date:** 4-4-08

**Time:** 9pm eastern time

**10 Attending**

## **Overview:**

Introductions were made and each ECD case represented was shared. An agreement was made to meet again.

## **Summary of 4-4-08 Meeting:**

Began by stating what participants hoped to get out of the chat. This included:

- A chance to chat with people who understand where we are

- Support

- Info, inspiration, friends

- Ideas on ways we can communicate with each other

- A way to connect and support each other across 'the miles'

- Connections

- How long it took until a diagnosis was achieved

- Feeling that we have people out there battling ECD with us and we are not alone

- Onset of symptoms, age at dx, how long is it estimated you've had ECD, drugs, treatments, doctor's names

Next each participant shared their experience with ECD. The information shared was collected and put into the ECD Case Log that can be found on the [www.erdheim-chester.org](http://www.erdheim-chester.org) website under the 'Patient to Patient | Case Log' selection.