

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 website under the 'Patient to Patient | Case Log' selection.