

Summary of ECD Global Alliance chat held on Saturday 5th September 2009

8 Present

- One member on the chat gave their first talk on ECD last Friday, which went very well. They are thinking of approaching the local radio station to offer to give an interview on ECD.
- A member has suggested setting up a meeting/meetings to allow everyone to get together. The East Coast and mid-west were suggested as possibilities.
- Dr. Haroche has been in contact with one patient (who he saw in March) with suggestions for further treatment. Pegylated interferon and/or dasatinib (used in the treatment of chronic myeloid leukemia) have been suggested.
- One member is working on producing a video on ECD. Ideas for the video should be emailed to stanceforlance@hotmail.com. Articles/suggestions for the next newsletter may also be emailed to this address.
- Another member is considering making a video for You Tube and is also producing tee shirts to raise awareness.