

Summary of ECD Global Alliance chat held on Saturday 19th March 2011

8 Present

- A new member was welcomed to the chat. This patient (aged 31) was diagnosed with ECD in February and has spent the last five years seeking a diagnosis. Their main symptoms are poor balance and stiff legs.
- One patient reported that they are doing well on Kineret. The treatment seems to have helped a great deal with mobility and relief of leg pain.
- Several patients on the chat (or represented on the chat) mentioned that they suffer from weakness and/or tremors in the hands.
- A recent radio programme on CBC which featured interviews with two members was heard by at least one million listeners.
- The next chat will be held on Saturday March 26th at 3pm EST.