

Summary of ECD Global Alliance chat held on Saturday 11th December 2010

10 Present

- There will shortly be a press release to announce the research grant that the ECD Global Alliance will be awarding. It will be sent to everyone so that they can send it to their local press if they wish.
- A new member was welcomed to the chat and introductions were made. Their 63 year old spouse was diagnosed with ECD two weeks ago. The patient has no symptoms; the diagnosis was made from an incidental finding on an MRI scan of the knee and confirmed by a bone marrow biopsy. It was discussed that that chat room takes a little getting used to at first, but gets easier when you start to learn who everyone is.
- The new member explained that at present they are looking for experts who will be able to review the situation and make some recommendations on how to proceed. Various suggestions for contacts and sources of information were made.
- A member described the difficulties involved, physical and mental, in being both a patient and a caregiver.
- Dr. Vaglio's study in Italy has now been approved. Information will be sent shortly. Dr. Vaglio will be looking to receive medical records from as many patients as possible, for those who have been diagnosed for six months or longer.
- The ECD Global Alliance is still working with the NIH and hopes to hear that their study will be approved shortly.
- There was a question posted at the end of a chat held recently, asking if any patients had suffered from tremors. A message was posted at the end of this chat from a patient who said they did have a problem with tremors and loss of function in their left hand. Overall motor skills, balance and co-ordination have been affected because of this. It is thought that the tremors are due to a lesion in the cerebellum.
- Christmas greetings were exchanged.
- The next chat will be held on Saturday 18th December 2010.