

Summary of ECD Global Alliance Internet Chat 07 April 2012

7 Attendees

- There was a message left by someone whose father had been diagnosed through a bone biopsy, after some length of time. He lives in rural Canada, and his doctors haven't started treatment. He has many of the symptoms that we suffer from, but his doctors often say that they are not related to the ECD. It was suggested that a written summary of the case, including symptoms and test results, would be helpful.
- On the Global Alliance web-site, there is a list of Doctors, who know about, and/or are interested in ECD. It is difficult to find doctors to help with such a rare condition. (Author's note: I went from the North of England to Paris!! I was a family doctor in the UK for 20 years. I had never heard of ECD. I have never met another patient face-to-face in the seven years since I was diagnosed).
- On the chat, there were less people than usual. One member suggested that people were off hiding Easter eggs, or hunting for them! It was said that the most difficult part of hiding the eggs, was not eating them, before they had been hidden. Many of us had not got involved in "the hiding, or the hunting" for some years.
- The funeral has taken place for our member who died recently. We were pleased to hear that, "We had the most marvelous funeral send off for T..... on Monday and a terrific party afterwards".