

Summary of ECD Global Alliance chat held on Saturday 26th March 2011

7 Present

- A very successful Fun Run was held last weekend in Louisiana. There were over 150 participants who all received ECD T-shirts. It was a great awareness raising event as well as a money raiser. Sincere thanks were expressed to the organizer. It is planned to write a guide for others to use if they are interested in organizing a fun run in their local community.
- The NIH have informed the organization that they are close to being able to start work on their study on ECD.
- Dr. Vaglio (in Italy) is still looking for as many records as possible for his study. Please keep trying if you haven't already sent your records.
- One patient reported that they feel tired all the time at present.
- One patient is in hospital with a kidney and bladder infection.
- There was a brief discussion on the subject of remission in ECD. Wikipedia defines remission as 'the state of absence of disease activity in patients with a chronic illness with the possibility of return of disease activity'. The problem with using the term in relation to ECD patients is that not enough is known about ECD to be always able to make definitive statements. Of course, it is always good news when the progress of the disease appears to have been altered, whatever the terminology used.
- The next chat will be held on Saturday 2nd April 2011 at 3pm EST.