

## **Summary of ECD Global Alliance Internet Chat 18 Feb 2012**

# Attendees: 9

- A member, who has been having prolonged back problems, has started to have pain-killing injections, to his spine. He is happy with the results so far. We all hope this improvement continues.
- We were reminded of the need to keep up with our fluid intake. A member became unwell this week, having forgotten to eat and drink enough during the day. He was unable to talk, to move his legs, or open his mouth. Fortunately, he is now better, although his balance is still poor.
- A member asked about problems with the circulation of blood in the legs. Someone with swelling has been told that they have venous insufficiency, and has been advised to wear support stockings.
- A member has been put on 2 medications to try to control his blood pressure. He, and his team, thinks that the rise in pressure is a side-effect of kineret. He has asked his doctor whether this is a known side-effect, but has had no answer yet.
- Is anyone aware of anything happening in their community to recognize Rare Disease Day on Feb. 29? There is a 1 minute video about rare diseases at this web address- <http://www.rarediseaseday.org/solidarity>
- Some of the members, and relatives, will be lobbying on Capitol Hill on Feb 28 for rare diseases.
- One European member, who has been having some difficulties with her work situation, has decided to go back to a more secretarial job, rather than into a project management post.
- Our "soon to be weds" have been taking arrangements further. A deposit has been placed for the tux hire. The male half of the married couple-to-be, has re-started writing his blog, and this is the URL <http://www.theperfectfocus.com/>
- One member came on who has been helping her daughter to clean out the garage! And she is doing some cooking too!
- A member came on whose daughter had died from the effects of ECD last year. She was welcomed back. She has been writing some of the story of her daughter's illness, and how it has affected everyone close to her.
- Our member who lives in L.A., gave us all the "wonderful" news, that the weather over there is magnificent! The rest of us were all "very pleased" for him!
- Our member having the computer problems said that the oncologist is very pleased with his progress. He will try his very best to be with us all next week.