

Summary of ECD Global Alliance chat held on Saturday 12th February 2011

8 Present

- A patient who uses the fentanyl patch to cope with leg pain is usually able to make a 72 hour patch last for 96 hours.
- A patient received news this week that the approval for payment of Kineret has been denied, as it is not an approved treatment for ECD. There were no other patients on the chat who take Kineret, although it is used by a least a couple of patients in the group.
- Rare Disease Day is February 28, 2011. The purpose is to raise awareness of rare diseases and the related issues. You can find out more at the following address: <http://www.rarediseaseday.org/>. If you are on Facebook the page supporting Rare Disease Day is <http://www.facebook.com/RareDiseaseDay.US>.
- One patient is finding difficulty swallowing and may choke even when just swallowing saliva. Several other patients on the chat mentioned that they also have this problem. There is a piece on the ECD Global Alliance website (written by a member) which suggests ways of coping with this. (See <http://www.erdheim-chester.org/SwallowingTechniques.html>)
- One patient finds that their legs do not move very easily when transferring to and from a wheelchair. Several patients mentioned that their legs feel weak when they first stand up. Several patients have balance issues and find that they are particularly unstable when they first get up.
- The next chat will be held on Saturday 19th February at 3pm EST.