

Summary of ECD Global Alliance chat held on Saturday 24th April 2010

5 Present

- Several patients commented that the weather, and changing air pressure, strongly influence how they feel. Two patients find that the level of pain in their legs is affected by the weather.
- A patient who recently started taking Gleevec is doing very well. They have much more energy and are able to take on tasks in the house/yard that would previously have been impossible.
- A patient has found that stopping steroid treatment two weeks ago has made them feel unwell.
- One patient reported that they have suffered a lot of pain recently. Granulomas on the ribs and lungs cause pressure leading to a loss of voice. A recent CAT scan showed an increase in granulomas.
- As there were so few people on the chat today, it was agreed to defer the question for discussion until the following week. The question will be raised during the chat rather than being sent out beforehand.
- The next chat will be held on Saturday 1st May, at 3pm EST.