

Summary of ECD Global Alliance chat held on Saturday 10th July 2010

8 Present:

- If anyone is in need of advice regarding patient assistance medicine, there are a couple of websites listed under 'resources' on the ECD Global Alliance website that indicate if there is a program for a particular medicine. The website will allow you to print a form to send to the pharmaceutical company.
- One patient taking Gleevec continues to do well; they have much more energy than previously and are pain free.
- One patient with lung problems is still using oxygen full time. No further treatment options have been suggested.
- A patient in the group described the how difficult it was at present caring for their partner, who has serious health issues themselves at present. Members offered their prayers and support.
- One caregiver described how their relative was suffering from depression, caused by the disease and the limitations it placed on their life.
- A doctor treating a patient with ECD has mentioned the possibility of using the drug thalidomide to treat the disease.
- There are a few members who have been diagnosed with both non-Langerhans and Langerhans Histiocytosis. An ECD doctor expressed the view that this may not be uncommon amongst ECD patients.
- The question for discussion this week was 'We tend not to discuss pain and the medications we take for it. Would some of you share what medications you are on, how it affects your life and how you feel when taking pain medications both physically and mentally?'
 - one patient is on 12mcg 72hour fentanyl patches, which work extremely well
 - one patient takes 6 Advil a day, with 20mg of prednisolone
 - one patient takes methadone, 10mg once a day, and occasionally takes Tylenol
 - one patient has taken Lyrica for nerve pain, and was unsure as to whether it was effective in reducing pain, they had previously tried fentanyl which was not effective for pain relief.