

Summary of ECD Global Alliance chat held on Saturday 13th March 2010

9 Present

- Two newly diagnosed patients had contacted the group this week.
- One patient has been ill for four weeks now with a 'cold'. Their blood counts were too low this week to have chemotherapy treatment. This patient is also suffering from a lot of bone pain; it was suggested that the drug Kineret, which has been very helpful for another patient in the group, might be considered.
- One member is composing a list of fund raising ideas for when the group receives its tax exemption status and any fundraising ideas would be very welcome. If all goes well the group may receive tax exemption status in 2-3 weeks. There are still some issues to sort out but things are looking hopeful at this point.
- One patient recently started Gleevec and is doing well; they have more energy and have not had any side effects.
- Members were thanked for their efforts in promoting Rare Disease Day on February 28th. The Wall Street Journal published an article and there were a number of local papers that had articles on the subject.
- One patient reported that the morning sickness they had suffered from recently had now gone. The patient was not sure of the cause of the sickness.
- The group now has a flip video camera. If any members are planning to meet, this camera could be sent to the member (s) to film the occasion!
- There has recently been a TV program on rare diseases, which included a centre where patients go to stay for a week and have extensive tests. It was thought that this was the Undiagnosed Program run by NIH.
- One patient's doctor has questioned whether patients with granulomas also have high cholesterol.
- One patient described the difficulties they face looking after their spouse, who has dementia, and coping with the illness of ECD themselves.
- It has been agreed that a question will be posed each week for members to consider and then discussed in the chat the next week. The question for this week is: 'Share what your experience was when you first were told of your illness; being told that it was serious; that there was no treatment or cure; feeling alone in dealing with the medical maze; how this changed your life and that of your family etc.'
One member commented that they were thrilled to finally have a name for the illness. Another described how they prayed for a diagnosis that never came.

This topic will be discussed more fully in the chat next week, and everyone's contribution would be valued.

- Members shared at the end of the chat how valuable they found the support and friendship within the group.
- The next chat will be held on Saturday 20th March, 3pm Eastern Time.