

Summary of ECD Global Alliance chat held on Saturday 1st August 2009

10 Present

- One patient is being gradually tapered off interferon, they are stable and have been for some months
- A new member (and newly diagnosed patient) was welcomed to the group.
- There was a discussion about the different types of treatment that patients have had. One patient on the chat had received fludaribine, which they felt had not been effective. Two patients on the chat had experience of interferon (interferon has been taken by a number of members of the group) and they had only had minimal side effects. Three patients had received cladribine (2-cDA), one said they had tolerated it well, another felt a little sick. One patient has recently commenced Gleevec and has experienced some side effects but feels the drug is helping.
- Cardiac involvement in ECD was discussed. Three patients had experience of cardiac involvement. One patient described how they had recently had a pericardial effusion and had fluid drained from the heart. This patient recently had a pericardial window to relieve fluid build-up around the heart. Another patient had also had a pericardial window.
- A question was raised as to whether the patients on the chat still went to work. Most did not, although one patient was still working six days a week. One patient hopes to return to work when their present course of chemotherapy is finished.
- Two patients on the chat had experienced spinal involvement.
- Some patients described how they felt better when they ate whole foods, one patient had cut out caffeine and thought that they benefited from this.
- It was suggested that it would be a good idea to update the patient log on the website. This may be found on the website by clicking on 'Patient to Patient' and then clicking on 'Case Log'. Any suggestions on how to improve the information collected would be most welcome; these may be sent by email or discussed in the chat. Also any feedback on the website would be very welcome.
- Several patients on the chat discussed their experiences with stomach problems, it seemed unclear in some cases whether these were related to ECD. Some patients took omeprazole to relieve these symptoms.