

Summary of ECD Global Alliance chat held on Saturday 19th September 2009

10 Present:

- One patient is currently exploring possible ways of restoring their sight, which was lost as a result of ECD.
- One patient has a new doctor who has offered help with pain control and is also prepared to work with Dr. Arceci in considering the most appropriate treatment plan.
- A patient on Gleevec has been experiencing side effects (ankle pains and chills) although generally feels that Gleevec has helped a great deal.
- The Case Log on the website was discussed. This may be found under 'Patient-to-Patient' and then select 'Log'. The case log lists information such as date and age of patient at diagnosis, signs and symptoms, medications etc. If you have not sent in your information, you can do so by sending it to support@erdheim-chester.org.
- One member has been working on a project to produce tee shirts to raise awareness of ECD. Members on the chat expressed their appreciation for all the work that had gone into this. Please e-mail 'taylorisland@hotmail.com' if you would like to receive tee shirts for yourself and family. Please specify size, quantity and address to which the tee shirts should be sent.
- All the paperwork has now been submitted on behalf of the group to make us an official non-profit organization.
- One patient's insurance company has recently refused approval for cladribine; an appeal against this decision is planned. One member mentioned that they have received drugs from the manufacturer at no cost. One member offered to do a literature search to gather information on cladribine to help with the appeal. The suggestion of obtaining legal advice and utilizing a patient advocate was made.
- There was a brief discussion about how the side effects of interferon often decrease with time.
- Age of diagnosis was discussed; amongst the members on the chat the ages of diagnosis included 49, 45, 42, 34 and 29.