

Summary of ECD Global Alliance chat held on Saturday 23rd January 2010

11 Present

- Members were reminded to write to their state governor asking them to adopt February 28th as Rare Disease Day. Several members have already done this. If you have any questions or ideas for promoting Rare Disease Day, please email rjcmorgans@wildblue.net.
- Several members reported good news in terms of scan and test results.
- One patient has been tapering steroids and is now down to 6mg a day, they hope to be off the steroids by April/May. They commented that the tapering process had been difficult.
- One patient has just started on Gleevec, and so far has just had a little muscle stiffness.
- This past week the Genetic Alliance featured the ECD Global Alliance in their weekly report they send out to all members of their group, complete with a link to our website. Also, the GARD arm of the National Institute for Health has added a reference and link to our group on their website.
- There was a discussion on whether stress may trigger the onset of ECD. Several patients had experienced stressful events prior to diagnosis. Questions such as these emphasize the importance of an ECD registry, something the group is working on. In conjunction with Dr. Vaglio, the group is working on a questionnaire to send to patients. Anyone who would like to view and comment on the form should contact the group at the usual address. Dr. Vaglio is also working with the form but we will do our best to incorporate suggested changes before the form is sent to patients.
- Another wonderful Christmas card is nearing completion. Thanks were expressed to the talented member for all her work on this project.