

## Summary of ECD Global Alliance chat held on Saturday 23rd April 2011

7 Present:

- A patient in the group is interested in finding out about other patients experience with the drug Gleevec. Has it been of benefit to you? If so, how? Have there been any side effects? One patient on the chat said that the treatment seemed to help almost instantly but it was stopped after three months due to stomach problems. Overall, however, they feel the treatment was beneficial. One patient in the group has been on Gleevec for a number of months with worsening symptoms. If you were not on the chat, but would like to share your experience with this treatment, please leave a message in the chat room which may be accessed any time.
- A patient who has been very ill recently with kidney problems is hoping that they will not require dialysis after this weekend. Recent blood results indicate that the kidneys are working again. However, the patient is very weak and is looking into getting a lift to aid transfer between chairs.
- One member has recently approached the B101 radio station to see if the Trans-Siberian orchestra would consider donating to the ECD Global Alliance (the radio station promotes the orchestra).
- Another member has been approached by their local hospital foundation for ideas for events which could be held to promote Rare Disease Day next year. One member mentioned that the rare disease website has a whole section of ideas (<http://rarediseaseday.us>) Some ideas mentioned on the chat include hosting a talk on rare diseases for the hospital staff and community and asking the hospital to arrange a lunch for the staff to promote rare disease day. One member mentioned that NORD can supply trinkets that may be handed out and also posters etc.
- Patients in the group were encouraged to send their medical records to Dr. Vaglio for his ECD study; as yet he hasn't received many. Information about the study, and the items that are required are on the ECD website (<http://www.test.erdheim-chester.org/VaglioPhenotypeStudy.html> ) and [http://www.test.erdheim-chester.org/DataFiles/PresentationsAndArticles/Vaglio\\_Phenotype\\_2010\\_12\\_Checklist.pdf](http://www.test.erdheim-chester.org/DataFiles/PresentationsAndArticles/Vaglio_Phenotype_2010_12_Checklist.pdf)). Basically the items required are: a) a report from your doctor(s), b) copies of scans, c) blood test results, and d) some forms you will need to complete and sign. If you have any difficulties obtaining this information, please send a request for help to the usual email address ([support@erdheim-chester.org](mailto:support@erdheim-chester.org)).
- ECD t-shirts are still available (except for the large size). \$25 will cover the cost of a shirt and postage. Please send orders to ECD-GA, PO Box 775, DeRidder, LA 70634.
- The next chat will be held on Saturday 30<sup>th</sup> April at 3pm EST.