

Summary of ECD Global Alliance chat held on Saturday 7th May 2011

7 Present

- There was a reminder that there is a list of physicians on the website who have some knowledge of /experience of ECD. The list can be found at <http://www.erdheim-chester.org/PhysicianResources.html>). Please feel free to share these names with your treating physicians if you feel this would be helpful.
- Members were reminded about submitting medical records for Dr. Vaglio's study. Details of the information required are on the website. If you need any help in gathering information or have any questions, please do ask. (For more information see, <http://www.erdheim-chester.org/VaglioPhenotypeStudy.html>.)
- The website is being updated at the moment. If anyone has any suggestions for what should be included, please send an email to support@erdheim-chester.org.
- Several members have been wearing the ECD t-shirts recently and they seem to have helped in raising awareness of the disease. T-shirts are still available (although not currently in the large size) from P.O. Box 775, DeRidder, LA 70634.
- There was a discussion on the subject of applying for social security disability. One patient applied in January 2005 but was only successful in receiving the benefit in September 2008. Another member commented that in order to be successful you need to be well prepared and have good documentation from your doctor. Of the members who have applied in the organization, most cases have gone to appeal. The more information we are able to share on this subject, the easier it may be for future requestors. It was suggested that it would be good if the organization had a volunteer to collate the documentation that patients would need when applying for social security disability. If anyone is interested in doing some work on this, please send an email to support@erdheim-chester.org.

The Social Security Office now has a program called 'Fast Track' (<http://www.socialsecurity.gov/pressoffice/pr/fast-track-disability-process-pr.htm>) and if a patient has one of the diseases on the fast track list, the approval process is much quicker. It would be useful to look into what would be required to get ECD onto this fast track list.

- Members wished each other a Happy Mothers Day.
- The next chat will be held on Saturday 14th May 2011 at 3pm EST.